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UNIVERSITY OF CAPE TOWN
IYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

**Seeing HIV through the eyes of perinatally infected adolescents living with
HIV, on antiretroviral treatment**

A mini-dissertation submitted to the School of Public Health and Family Medicine

In partial fulfillment of the award of a Masters of Public Health

By

PEARL HOLELE

STUDENT NUMBER: HLLPEA002

SUPERVISOR: DIANE COOPER

CO-SUPERVISOR: LINDA-GAIL BEKKER

13th February 2012

Dedication

I dedicate this thesis to my beloved mother, Tebelelo Holele. Thank you for all your support. You truly are “the wind beneath my wings”.

University of Cape Town

Abstract

Purpose

As perinatally infected adolescents living with HIV (ADLHIV) grow older and gain a greater sense of independence, disclosure issues and adherence to antiretroviral treatment (ART) have become major concerns. However, research on how adolescents view and cope with these challenges remains limited, especially in Sub-Saharan Africa. We explored ADLHIV's understanding of their infection and its perceived effects on their wellbeing, and ultimately, on their attitude towards life-long adherence to ART.

Methods

To this end, a literature review was undertaken, to explore existing literature on experiences of adolescents living with HIV (ADLHIV), on antiretroviral treatment (ART). The review included both qualitative and quantitative studies, since 2000, with particular attention given to research conducted in the context of sub-Saharan Africa. Studies reporting on psychosocial factors and how these impact on adherence were sought. To this end, 4 major themes viz: knowledge, experience, disclosure and adherence served as the search engine drivers. A total of 24 perinatally infected male and female ADLHIV, aged 10-15 years, attending an adolescent ART clinic in South Africa, were included in this exploratory study. 12 in-depth qualitative interviews and 2 focus group discussions, were conducted. Qualitative data were analyzed using grounded theory. Ethical approval for the study was granted by the University of Cape Town Health Sciences Faculty Human Research and Ethics Committee. In addition, consent to conduct the research was granted by the Western Cape Provincial Department of Health, and the Gugulethu Community Health Centre/Hannan Crusaid antiretroviral clinic. Written consent to participate, and for the use of an audio-recorder, during the interviews, was obtained from the legal guardians of each of the study participants, in addition, assent was obtained from all the study participants.

Results

Most of the adolescents demonstrated good knowledge and understanding around HIV, how it affects their health and the need for life-long ART. There was general acceptance, but also occasional resentment, anger and frustration regarding HIV and the need for life-long treatment. Nonetheless, their experiences were mostly positive, despite the negative effects of stigma and community attitudes. Knowing that there are others like them, also had a significant impact on how they experienced HIV. Many expressed appreciation for the effects of ART in keeping them healthy, allowing them a normal life and hopefulness about the future.

Conclusion

Despite the challenges of living with HIV, adherence being the major one, most of the young adolescents have good insights regarding the need for life-long ART and genuine motivation to remain adherent.

Key words: Adolescent, HIV, ART, Adherence, Attitudes and perceptions.

DECLARATION

I,, hereby declare that the work on which this mini-dissertation is based, is my original work. Neither the whole work, nor any part of it has been or is to be submitted for another degree in this or any other university.

Signature:

Date:

University of Cape Town

Acknowledgements

Pearl Holele developed the proposal, oversaw fieldwork, analysed all the data, wrote the literature review and manuscript. Professors Diane Cooper and Linda-Gail Bekker gave input and guidance.

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Part A: Protocol

Introduction and Background

The prevalence of HIV among children under the age of 15 in South Africa was estimated at 2.5% in 2008, mostly from perinatal transmission (Grey, 2009). The introduction and subsequent roll-out of antiretroviral treatment (ART) has led to a dramatic improvement in the survival rate of HIV+ children in this country. With the largest ART programme in the world to date, approximately 32 000 children under 15 years were noted to be on treatment in 2007 (Davies et al, 2009). Furthermore, a study looking at treatment outcomes of HIV positive children who access ART under the age of 16 showed a 7.7% mortality and 81.1% retention in care 3 years following ART initiation (Davies et al, 2009).

Thus, due to ART, an increasing number of children in Sub-Saharan Africa are surviving and reaching adolescence. However, a study by Nachega et al. (2009) showed that ART adherence among adolescents was significantly lower than that of adults, which led to poorer virologic and immunologic outcomes. In this study, it was shown that “adolescents were approximately 50% less likely than adults to maintain perfect adherence at all time points” (Nachega et al, 2009, p. 68). In view of these findings, a new frontier of challenges, where this epidemic is concerned, has now been reached regarding this particular population. Disclosure issues, adherence to ART and transmission of resistant HIV have become major concerns. The latter two issues especially, could potentially pose a serious public health challenge in the near future (Wiener et al, 2007).

Furthermore, adolescents in general, pose a real challenge to health care givers in terms of knowing and having their needs met adequately. Poor health seeking behaviour due to fear, denial or cultural perspectives, inability to communicate and/or express themselves or their needs clearly, and a general wariness of adults, are some of the contributing factors (Augustine, 2002). In addition, adolescents are generally perceived by adults as a difficult group of patients because of the complexity of their status as adolescents, going through the challenges of adolescence. The consequence has therefore been that insights pertaining to their needs when it comes to health care services have remained fairly limited. In addition, historically, adolescent health has been a fairly neglected area of medicine, which has resulted in a severe lack of skilled health care givers with specialised training in the management of adolescent health.

Adolescents with chronic diseases such as HIV are expected to assume greater and greater responsibility for their disease management as they grow older and gain a greater sense of independence. In addition, they have to make decisions about disclosure to peers and sexual partners, and risk the possibility of rejection and/or stigmatisation from peers. These challenges tend to impact negatively on their adherence (Marhefka et al, 2008; Wiener et al, 2007). For this emerging population, how they view and cope with these challenges in the worlds that they live in necessitates further studies (Wiener et al, 2007).

There is paucity in research data on how young adolescents living with HIV experience HIV and ART; what their knowledge, understanding and views are; how socio-cultural influences impact on these experiences and subsequently on adherence; and finally, how they see the future. Even more importantly, this area of research, on young (<15years), perinatally

infected adolescents living with HIV (ADLHIV), remains fairly neglected in sub-Saharan Africa. The focus, so far, has been on adherence in association with virologic outcomes, or care-giver characteristics and influences. Perhaps it's the fact that their age and therefore vulnerability as potential research participants poses serious ethical challenges. That, and also the need for special techniques and provisions upon their inclusion in research, has added to the reluctance of recruiting them as study participants. However, in order to stem the tide of poor adherence and sexual transmission of multi-drug resistant HIV once these adolescents become sexually active, there is a need to address the above issues while they are pre-pubescent and prior to their sexual debut, because failing to do so has serious public health implications; thus the study.

Problem Statement

Studies done on ADLHIV found factors such as forgetfulness, busy schedules, interruption of daily routine and stigma being cited as reasons for poor adherence (Nachega et al, 2009). Given the increase in survival of ADLHIV on ART, it is becoming increasingly important to identify barriers to adherence in this population in order to design appropriate and effective interventions. However, research in this area thus far has been fairly limited, especially in Sub-Saharan Africa (Nachega et al, 2009). In particular, research regarding adolescent HIV has been conducted mostly among adolescents in developed countries, mostly the USA. The majority of those studies have focused on older adolescents (>15yrs) with horizontally (behaviourally) acquired HIV. In addition, the focus, in this population, has been largely on adherence in relation to virologic suppression rates/outcomes, which is a real challenge with regard to adolescent care in HIV management (Williams et al, 2010). And finally, the research methods have mostly been quantitative (Grey, 2009).

There is thus a need to look at younger ADLHIV (<16yrs), in a developing country e.g. South Africa. Focusing specifically on adolescents with a history of vertical transmission, gaining insights into their experience of HIV and ART, i.e. attitudes and perceptions, and how these affect their adherence to ART, will be particularly valuable in understanding barriers and facilitators to adherence. In addition, given the gendered nature of the HIV epidemic in sub-Saharan Africa, examining gender issues and cultural influences among perinatally infected adolescents and how these factors impact on their experience of HIV in their communities and ultimately their adherence to ART, is pertinent.

Study Aims

The primary aim of this study is to attempt to see HIV through the eyes of a young, perinatally infected, asymptomatic ADLHIV, by exploring what their understanding of their illness is and its perceived effects on their health, body and self-image, in order to develop novel and effective ways of meeting their healthcare needs.

Secondly, to examine how socio-cultural factors such as gender, cultural influences and community issues, impact on the adolescents' experience of HIV in the communities they find themselves in. Hopefully, developing such insights can aid in more appropriate messaging regarding HIV and the importance of adherence for young ADLHIV on ART.

Research Questions (These will form the basis of the qualitative interview questions)

1. How does the young, asymptomatic ADLHIV perceive HIV and the importance of adherence to ART?

Sub-questions:

- What are the attitudes, knowledge and experiences among young perinatally infected ADLHIV with regards to HIV?

- What are their opinions and understanding of the need to continue taking medication in order to stay well, i.e. adherence to ART?
2. What are the key factors that affect ADLHIV's perceptions with regard to their HIV status?
Sub-question:
How do socio-cultural factors such as, gender, cultural influences and community attitudes impact on the ADLHIV's experience of HIV and ultimately on their adherence to ART?
 3. How do they see the future, living with HIV?

2. METHODOLOGY

2.0 Study Methodology

2.1 Study design

This is a qualitative study using in-depth interviews and focus group discussions. Drawings will be used as probes during in-depth interviews, to aid in drawing out information from the study participants, especially the 10 - 12 year olds.

2.2 Study population

The study population will come from the Hannan Crusaid adolescent ARV clinic, which is part of the Gugulethu Community Health Centre. Gugulethu is a peri-urban settlement in the Klipfontein sub-district of Cape Town, with a combination of formal and informal houses. Out of a total population of ~ 350 000, the unemployment rate is approximately 57%, and about 81% of the population lives in informal housing (Bekker et al, 2006).

The Hannan Crusaid adolescent ARV clinic was launched in 2008, and primarily provides ART to ADLHIV from the Gugulethu area between the ages of 10 and 19 years, as per WHO definition. This service is provided in an adolescent friendly environment that takes into account adolescents' challenging developmental needs in accordance with the Youth Friendly Services initiative by Lovelife (Augustine, 2002). Given that the PMTCT programme coverage in developing countries was only 45% in 2008, (Richter et al, 2010), the majority of the adolescents attending this clinic also have a history of vertical transmission of HIV, and many of them were diagnosed and had their treatment initiated at Red Cross children's hospital. They are initially transferred into the main Hannan Crusaid ARV clinic, which has been providing adult and paediatric ART services to the Gugulethu community since 2002. They are then transferred into the above clinic soon after their 10th birthday, and full disclosure is a pre-condition, prior to the transfer. Doctors, nurses and counselors dedicated to the adolescent clinic facilitate the delivery of care.

The Hannan Crusaid adolescent ARV clinic is chosen because of several unique aspects, viz: this adolescent clinic functions primarily as a referral facility, therefore all the adolescents seen at this facility are HIV+ and on ART or are being worked up to start ART. It does not provide additional services such as VCT testing, Family Planning or TOP services. This is what distinguishes this clinic from other youth clinics e.g. in the Khayelitsha sub-district, where such services are offered to both HIV- and HIV+ youth.

This population is chosen because: (a) they have all been on ART since early childhood, (b) they have all been attending the Hannan Crusaid adolescent ARV clinic for more than 1 year, and they all know their HIV status, (c) they are currently at various stages of development physically and psychologically, (d) they share similar backgrounds in terms of: geographic area, culture, schools, socio-economic circumstances and education levels of the care-givers, (e) adherence, now that they're a little older and no longer entirely dependant on their care-givers, has become a major issue for many.

The study population will consist of HIV+ adolescents on ART between the ages of 10 and 15 yrs. Study participants will need to meet the following inclusion criteria: (a) Infection through vertical transmission, (b) ART initiation prior to age 10, (c) Hannan Crusaid ARV clinic attendance since <10 years old, (d) they reside in the Gugulethu catchment area, (e) The study participant must have one principal legal guardian (Parent, Granny or Aunt/Uncle) who assists with medication and clinic attendance. Recruitment will be done in a manner that is representative in terms of age and sex.

2.3 Sampling and Recruitment

Once consent to conduct the research and ethical approval for the study has been granted by the Western Cape Provincial Department of health and the UCT Health Sciences Faculty Human Research and Ethics Committee, respectively, recruitment of study participants will commence.

Recruitment of participants into the study will be done via purposive sampling, common in qualitative research. This manner of sampling will ensure that adolescents who are chosen meet the inclusion criteria as set out in the "Study Population" section above. Due to the nature of the questions, purposive sampling will also ensure the inclusion of adolescents with some knowledge about HIV and the effects of ART. In addition, purposive sampling will also ensure that they are a group who share a lot in common, such as: geographic area, schools, socio-economic circumstances, education levels of the care-givers and cultural background, to allow for meaningful comparisons.

Due to the explorative nature of the research, and also because the study aims at taking an in-depth look at the subject at hand, a total of 12 in-depth interviews will be conducted. The study participants will be categorised according to age and sex, and recruitment will be done in a manner that is representative in terms of these two categories.

Two focus groups, consisting of a total of 12 participants, will be divided into two groups as follows: 10-12 yr. olds (6 participants), and 13-15 yr. olds, also consisting of 6 participants, and once more, recruitment will be done in a manner that is representative in terms of these two categories.

3.0 Data Collection Methods

This study will make use of qualitative tools and techniques of data collection.

3.1 Study Duration

The entire study will take approximately 6 Months from recruitment of study participants to data analysis and dissemination.

3.2 Data Collection Tools

The data collection tools that will be utilized for this study will include in-depth interview guides and focus groups interview guides; and will utilise drawings, which will be used as probes during in-depth interviews. Studies have shown that art can be an effective tool when conducting interviews with children. They have been found to be more effective communicators through art than verbally, and much can be revealed in terms of experiences, thoughts, hopes and how they make sense of confusing issues in their worlds (Kortessluoma et al, 2008).

3.2.1 In-depth Interviews

Qualitative in-depth, one-on-one interviews will be conducted with each participant. Due to the sensitive nature of the topic, namely HIV, the privacy and individual attention provided by a one-on-one interview should enable the participants to talk more freely about their personal feelings and experiences. Disclosure issues, care-giver support issues and home environment enablers or challenges will also be best explored in this setting. In addition, one-on-one interviews will create space for these young adolescents to express their individual perceptions and feelings regarding how they see the future; and their concerns regarding their future as HIVpositive individuals in society, free from peer pressure influences. It will also provide insights into how they understand and/or what they make of all that is happening to them with regard to HIV and ART, and how it impacts on their daily lives.

The main data collection technique that will be used will be in-depth, semi-structured, open-ended interview guides. This technique will be used primarily to answer research question 1. As mentioned earlier, probes will be used during the interviews. One means of probing will entail the use of drawings to aid the adolescents in demonstrating their understanding of the effects of HIV and ART in their bodies. Background socio-demographic information will be collected, such as: age, sex, grade in school, who the primary care-giver is, duration on ART and how long they have been attending the Hannan Crusaid adolescent clinic for. Instead of being collected prior to the interview, these will be used instead as “ice-breakers” at the start of the interview. The interviews will be conducted at the Hannan Crusaid ARV clinic, in a counselling room, to ensure privacy. These will be conducted on a Tuesday afternoon during the adolescents’ clinic visits, so as not to interfere with the study participants’ school time.

Since the adolescents are primarily Xhosa-speaking, each interview will be conducted by a trained fieldworker in Isi-Xhosa, and will last approximately one hour. The researcher will play the role of overall facilitator, overseeing the entire data collection process, and ensuring the proper use of the digital recording device. However, in order to avoid the “white coat” effect, the researcher will not be present during the actual interviews. Each recorded interview will be transcribed verbatim and then translated into English, for ease of analysis. Permission will be sought from the study participant and legal guardian for the use of an audio-recorder during the interviews.

3.2.2 The two focus group interviews will also be conducted at the Hannan Crusaid ARV clinic, in a counselling room, to ensure privacy. They will also be conducted on a Tuesday afternoon during the adolescent’s clinic visits, so as not to interfere with their school time. Focus groups will allow participants free expression in a group environment. This technique

will be used primarily to answer research question 2. The focus during these groups will be to share ideas regarding their health and experiences in their neighbourhoods, schools and communities; How they feel they may be perceived by peers and the community that they come from, cultural influences and how that affects their perceptions, understanding, feelings regarding their particular condition/status as HIV+ youth, stigma, etc. The participants chosen for focus group interviews will be a totally different sample that will provide fresh, different and perhaps even completely unexpected perspectives on the issues around HIV and ART to be discussed.

Similar to the one-on-one interviews, each focus group interview will be conducted by a trained fieldworker in Isi-Xhosa, and will last approximately one hour. Once again, the researcher will play the role of overall facilitator, overseeing the entire data collection process, and ensuring the proper use of the digital recording device. As with the one-on-one interviews, the researcher will once again not be present during the actual interviews in order to avoid the “white coat” effect. Similarly, the recorded interviews will be transcribed verbatim and then translated into English, for ease of analysis. Each interview will last an hour. Permission will be sought from the study participant and legal guardian for the use of an audio-recorder during the interviews.

3.3 Pilot Study

A pilot study will be conducted to test the overall feasibility of the data collection methods and the study instruments. Especially in view of the age and thus vulnerability of the study participants, checking the appropriateness, understanding, clarity and flow of the interview questions will be essential and revisions will be made where necessary. The pilot study will be conducted in the same facility by the researcher and a trained, Xhosa speaking, fieldworker. A total of 5 adolescents varying in age from 10 – 15 years will be randomly chosen during clinic visiting time, for interviewing. Those chosen will be the ones that are accompanied by a legal guardian, so as to obtain consent, prior to the interview. This process will be carried out over a two week period. The data gathered from the pilot study will not be included in the dissertation; in addition, the participants recruited for the pilot study will not be recruited for participation in the actual study.

4.0 Data Management

For confidentiality and security purposes, all data from this study (digital recordings of all interviews, transcripts and translated material) will be kept in a safe place (in a locked cupboard). Copies of transcripts and translated material will be kept on 2 separate hard drives (1 laptop and 1 external hard drive). In addition, all material will be stored on 2 separate flash drives. Copies of the audio-tapes will also be made and kept in a safe place, different from where the original copies will be kept. Nvivo data management package, which is one of many computer software packages used in qualitative analysis, will be used for this study, to facilitate data management and analysis.

5.0 Data Analysis

A grounded theory approach will be used to analyse the data. Data will be explored in search of common themes and patterns. Because data analysis is an iterative process, each one-on-one interview will be followed by a process that entails constant coding, reading, re-reading, rephrasing, analysing and verifying. This same process will be applied following each focus group discussion. In addition, in order to identify possible gaps in data collection, data

analysis will begin in the field and will continue throughout the data collection period. The analysis will then extend beyond this period, identifying possible themes and developing tentative explanations. There will be a constant search for core meanings of, opinions, thoughts, feelings and behaviour of the interviewees throughout the entire data collection and analysis process. This will be followed by an overall interpretation of the study findings, to demonstrate how themes relate to one another and ultimately how concepts answer or respond to the original study questions. Triangulation will be used to ensure rigor, by comparing findings with available data.

6.0 Ethics

Due to the age of the study participants, written, informed consent will have to be obtained from each of the participants' legal guardians first, followed by individual assent from each participant. The written consent will be translated into and conducted in Isi-Xhosa for ease of understanding. This will be done prior to the interviews. In addition, the parents/legal guardians will be assured that allowing their children to participate is purely voluntary and that they are free to withdraw their children from the study without fear of any penalties. In terms of assent, only those adolescents who give their assent will be recruited for the study.

The recruitment of such young and thus vulnerable study participants raises quite a few ethical concerns. (a) The parents/legal guardians may be concerned not only about their children being asked to speak to a stranger about sensitive issues such as their HIV status, social stigma, disclosure issues, loss suffered due to HIV/AIDS (commonly a parent), negative peer and community attitudes and perceptions, but also about the emotional and psychological effects of such discussions. (b) They may also be concerned that they will not be present during the interview to protect their children if they become distressed. (c) They may be concerned about the use of an audio-recorder, anonymity and confidentiality.

In order to set the parents/legal guardians at ease, the study has built in measures to allay these fears, thus: (a) A youth counsellor that the study participants are used to interacting and engaging with at the clinic and who, in addition, has been receiving on-going training in distress management and youth counselling, will be present during the interview and will be facilitating the process. (b) They will be given an information leaflet detailing the study purpose, the interview process, the questions that will be asked and who to contact for further information upon recruitment and prior to the interviews. (c) They will be assured of anonymity and confidentiality of all information shared during the interview in that the personal information shared will only be used as research data and will be managed in a manner that ensures anonymity and confidentiality. (d) They will also be assured that the interview process will be interrupted immediately if it causes undue emotional distress to the young participant, and necessary referrals made if sought. In addition, the respondent will be informed at the outset that if issues arise during the interview that involve abuse or severe depression that may lead to the participant subjecting themselves or others to harm, the interviewer may have a medico-legal obligation to report to a counsellor, nurse or doctor while informing the participant.

Similar to parents/legal guardians, the study participants themselves may be concerned about speaking to a stranger about very personal and very sensitive issues, mentioned above, and may feel particularly vulnerable without the parent/legal guardian during the interview. Once again, as mentioned above, the counsellor that they are familiar and at ease interacting with during their clinic visits will be present and will act as facilitator. The same measures will

be taken in allaying their fears and concerns as mentioned above. In addition, should the study participants feel the need for debriefing following one-on-one interviews or focus group participation, this will be provided by referral to either a counsellor or the facility social worker

The parents/legal guardians and young study participants will be assured that although the benefits of doing the study may not be felt immediately, however, since a study of this kind has not been done before, the information gained will hopefully be used to inform policy. In addition, health programmes will hopefully be developed that will address concerns and challenges highlighted in the study findings. Also, since many of the care-givers are experiencing problems with their adolescents' adherence now that they are old enough to take treatment on their own, programmes may be developed that will offer support to parent/legal guardians of ADLHIV. Furthermore, since the adolescents are also attending school, which poses challenges of its own, with limited peer and teacher support, the findings can be used to get the Education Department's buy-in to introduce support programmes in schools which will help towards adherence.

Both the parents/legal guardians accompanying the adolescents and the study participants will be offered refreshments and transport money for participating in the study.

In addition, as mentioned above, ethical approval for the study will be obtained from the UCT Health Sciences Faculty Human Research and Ethics Committee; and consent for the research will also be sought from the Western Cape Provincial Department of Health and the Gugulethu CHC/Hannan Crusaid ARV clinic.

7.0 Logistics

As mentioned earlier, since the adolescents are primarily Xhosa-speaking, and in order to avoid the "white coat" effect, each interview will be conducted by a trained fieldworker/interviewer in Isi-Xhosa and the researcher will not be present during the actual interviews. The fieldworker will be bilingual, have a bachelor's degree or equivalent skills in the social or health sciences, in addition to experience in qualitative interviewing and working with youth. We will use a training program used in qualitative methods training, usually used for other studies conducted in the Women's Health Research Unit (WHRU) at UCT, to conduct a 2-day training program for the interviewer/fieldworker. Training will focus on ensuring she/he has sufficient qualitative interviewing skills and on enhancing her/his knowledge of HIV, youth and ART. Training will follow standard procedures such as: an explanation of the rationale behind the study, review of key principles underlying qualitative research methods and interviewing, familiarisation with the procedures for the study including procedures and practice for interacting with health service staff, and procedure for the importance of participants being enrolled with full informed consent. Training will be conducted by the PI, Dr Holele, with advice from A/Prof Diane Cooper from the WHRU at UCT.

The researcher will therefore work very closely with a fieldworker, who is not only experienced in conducting qualitative interviews, but also trained to work with youth. The latter issue is especially important not only because the study participants are particularly young and vulnerable, but also because the subject to be dealt with is quite sensitive.

Therefore the interviewer/field worker will need to be able to establish good rapport with each interviewee and thus create an environment that will put the interviewees at ease and encourage them to speak freely. For this reason, it will be very useful to also include one of the clinic's youth counsellors, who is known to the study participants, as part of the team to assist during the interviews by acting as facilitator, especially since the researcher is also their doctor.

The researcher will play the role of overall facilitator, overseeing the entire data collection process, and ensuring the proper use of the digital recording device. In addition, the researcher will also be responsible for the following: (a) recruitment of study participants, (b) ensuring that there is written consent from the legal guardians of each study participant and that assent has been obtained from each study participant, (c) to ensure that the data collection instruments are functional and ready for use prior to each interview, (d) to oversee and supervise the overall data collection, transcription and translation process, since all of this will be conducted by the fieldworker, (e) training of the fieldworker and local assistant (clinic youth counsellor), to ensure clear knowledge and understanding of the aim of the research, the subject issues that will need to be covered, and in qualitative research techniques, (f) analysis of the data collected, transcribed and translated by the fieldworker.

7.1 Logistical Challenges

1. Recruitment Challenges:

- (i) Getting the young adolescents to agree to participate in a study that involves the use of a recording device, especially the one-on-one interviews. They may find this rather daunting.
- (ii) Getting consent from the participants' care-givers. Given the sensitivity of the topic and the age and thus vulnerability of the study participants, caregivers might have reservations in having their children participate in a research study.
- (iii) Since many of the adolescents are old enough to come to the clinic unaccompanied, getting the caregivers to attend with them for the purposes of participating in the research study may prove fairly challenging and time consuming.

2. Communication Barrier

Finding a fieldworker who is not only proficient in Isi-Xhosa, but one who is also able to interview young people and get them to freely discuss the issues around HIV and its impact on their young lives will pose a great challenge.

3. Transcription and translation

The process of first transcribing verbatim, and then translating the transcripts into English for ease of analysis will be very time consuming and costly. In addition, some of the gist of what is said may be lost during the process of translation. Therefore, due to time and financial constraints, the fieldworker employed may be called on not only to interview the study participants, but also to transcribe and translate the collected data material.

- 4. Finding a quiet space in a very busy clinic where the interviews can be conducted in a manner that ensures privacy and confidentiality may pose a challenge. However, since the clinic has a "chill room" for adolescents, this will probably be an ideal space to use, also because it is a familiar, comfortable and favoured space, it may assist in putting the study participants at ease for the purposes of the interviewing process.

8.0 Write-up and dissemination

The research study outcomes will be of interest to the National and Western Cape provincial departments of health, the Department of Social Services and the Education Department. In addition, it will also be of interest to health care providers involved in pediatric and adolescent HIV management specifically, NGO's involved in the development of youth health promotion and prevention programmers and services, and finally, the study participants and especially the parents and legal guardians of HIV+ children and adolescents.

The findings of this research will hopefully provide new insights into how young, perinatally infected ADLHIV view and understand their condition and the need to be on lifelong treatment. In essence, their perspectives and attitudes and how that affects their ability to adhere to their treatment. The insights gained will hopefully guide future adolescent health planning and policies nationally. At provincial level, it is hoped that the findings will provide health managers and health care providers with some guidance on novel ways of developing effective approaches to adolescent health promotion, prevention and service provision.

Since HIV affects more than just the individual, but the family and ultimately the community; and since many of these children have lost parents and are raised by relatives, commonly grandmothers, hopefully the research data will highlight some of the concerns and challenges that these young adolescents face daily. It is hoped that departments such as education and social services will join the health department in taking these issues into consideration during budget and resource allocation.

The researcher will organise a meeting at the clinic to give feedback to study participants, their legal guardians and health care givers about lessons learnt. In addition, the findings of the study will be presented to other researchers during workshops and conferences to stimulate further research into the subject. And finally, the article will be prepared for publication in a relevant journal such as, JAIDS (Journal of AIDS).

References

1. Grey, G. 2009. Adolescent HIV-Cause for concern in Southern Africa. *PLoS Medicine*, 7(2): 1-4, February 2.
2. Davies, M., Keiser, O., Eley, B., et al. 2009. Outcomes of the South African national antiretroviral treatment programme for children: The leDEA Southern Africa collaboration. *S Afric Med J*, 99(10): 730-737, October.
3. Nachega, J.B., Hislop, M., Nguyen, Hoang., et al. 2009. Antiretroviral therapy adherence, virologic and immunologic outcomes in adolescents compared with adults in Southern Africa. 2009. *J Acquir Immune Defic Syndr*, 51(1): 65-71, May 1.
4. Wiener, L.S., Battles, H.B., & Wood, L.V. 2007. A longitudinal study of adolescents with perinatally or transfusion acquired HIV infection: Sexual knowledge, risk reduction self-efficacy and sexual behaviour. *AIDS Behav*, 11(3): 471-478, May 1.
5. Augustine, J. 2002. Serving HIV-Positive youth. *Advocates for Youth*, November.
6. Marhefka, S.L., Koenig, L.J., Allison, S., et al. 2008. Family experiences with paediatric antiretroviral therapy responsibilities, barriers, and strategies for remembering medications. *AIDS Patient Care STDS*, 22(8):637-647, August 1.
7. Williams, P.L., Storm, D., Montepiedra, G., et al. 2006. Predictors of adherence to antiretroviral medications in children and adolescents with HIV infection. *Paediatrics*, 118(6):1745-1757, November 13.
8. Bekker, L., Myer, L., Orrell, C., et al. 2006. Rapid scale-up of a community-based HIV treatment service: Programme performance over 3 consecutive years in Gugulethu, South Africa. *SAMJ*, 96(4):315-322, April.
9. Richter, L., Beyrer, C., Kippax, S., et al. 2010. Visioning services for children affected by HIV and AIDS through a family lens. *Journal of the International AIDS Society*, 13(2):1-3, June 23.
10. Kortessluoma, R., Punamaki, R., & Nikkonen, M. 2008. Hospitalized children drawing their pain: the contents and cognitive and emotional characteristics of pain drawings. *J Child Health Care*, 12(4):284-300.
11. SOUTH AFRICA. LoveLife and the Department of Health, 2000. *Fostering health & well-being through youth friendly services*. Pretoria: Government Printer.

Part B: Structured Literature Review

Introduction and Background

Global HIV epidemic and adolescents

The fastest growing population worldwide are the youth, age <25 years, who make up at least a fifth, of the world's population. Of the 1.2 billion young people between the ages of 15-24 worldwide, an estimated 10 million are living with HIV (Wilson et al, 2010). Furthermore, 2.1 million children under the age of 15 are estimated to be living with HIV globally, the highest burden being in developing countries, where a significant number of children are living with HIV from perinatal transmission (Richter et al, 2010; WHO, 2009). Thus globally, the prevalence of HIV among the youth (< 25), has reached staggering proportions. Furthermore, studies show that the global HIV epidemic is largely youth-driven, with the 15-24 year age group bearing the highest burden (Wilson et al, 2010). In 2007, it was estimated that more than 1 million new HIV infections occurred among the youth between 15-24 years, which made up forty percent of all new HIV infections worldwide (Wilson et al, 2010; WHO, 2009). Sub-Saharan Africa is home to Sixty-three percent of the 15-24year olds living with HIV, i.e. 6.2 million (Wilson et al, 2010).

A fair proportion of the youth between ages 15-24 years, fall under the category of adolescents¹. Eighty-five percent of the 1.2 billion adolescents worldwide are located in the developing world (WHO, 2007). Perkins (2001) describes adolescence thus: "Adolescence begins with biological maturation (puberty), when young people must accomplish developmental tasks and develop a sense of personal identity. It ends when young people achieve self-sufficient adulthood as defined by society" (Perkins, 2001, pg3). Although the World Health Organisation (WHO) defines adolescence as those between ages 10-19 (WHO, 2010), they can be separated into early adolescence (10-14yrs), middle adolescence (15-17yrs) and late adolescence (>17yrs), (Perkins, 2001). Despite this, there is a tendency in the literature to combine all adolescents into one homogenous group, those <15years and those >15years, with the <15year olds being combined with paediatric cases, especially when gathering statistics regarding HIV prevalence and treatment outcomes.

In high-resource countries such as the United Kingdom, where ART has been available since 1996, the benefits have long been realised, rendering the survival into adolescence of perinatally infected children, the norm (Hazra et al, 2010; Jaspan et al, 2009). While only ~354,000 of the 2.1 million HIV infected children are on Antiretroviral treatment (ART),

¹ Defined by the World Health Organisation as youth between the ages of 10-19 years.

leaving a disproportionately high treatment gap, (WHO, 2010), the survival of perinatally infected HIV+ children to adolescence is increasingly recognised in sub-Saharan Africa, as the HIV epidemic matures (Ferrand et al, 2009; Bakanda et al, 2011; Davies et al 2009). In Southern Africa, perinatally infected children were not expected to survive beyond the age of 5 years, and approximately 50% were expected to die before the age of two years without ART (Ferrand et al, 2009). However, with increasing accessibility of ART, current trends suggest that the epidemic is headed in the same direction as in well-resourced countries, with the first generation of perinatally infected children reaching adolescence (Souza et al, 2010; Ferrand et al 2009; Bakanda et al, 2011; Jaspan et al, 2009).

The prevalence of HIV among children under the age of 15 years in South Africa was estimated at 2.5% in 2008, mostly from perinatal transmissions (Grey, 2009). The introduction and subsequent roll-out of ART has led to a dramatic improvement in the survival rate of HIV+ children in this country, and has effectively changed the face of the epidemic among perinatally infected children (Hazra et al, 2010; Souza et al, 2010). With the largest ART programme in the world to date in the country, approximately 32 000 children under 15 years were on treatment in 2007 (Davies et al, 2009). Furthermore, a study looking at treatment outcomes of HIV positive children who access ART under the age of 16 showed a 7.7% mortality and 81.1% retention in care 3 years following ART initiation (Davies et al, 2009). With the new National Department of Health ART Guidelines of 2010 (NDOH ART guidelines, 2010) rendering treatment immediately accessible to children <1 year, the above figures, especially the number of children on treatment, is expected to have increased significantly, although this may widen the treatment gap.

In view of these findings, a new frontier of challenges, where this epidemic is concerned, has now been reached regarding this particular population. Disclosure issues, adherence to ART and transmission of resistant HIV have become major concerns (Souza et al, 2010; Wiener et al, 2007). The latter two issues especially, could potentially pose a serious public health challenge in the near future (Wiener et al, 2007).

Objectives

The objective of this literature review was to explore existing literature on experiences of adolescents living with HIV (ADLHIV), on ART, i.e. their knowledge, perceptions and attitudes towards HIV and how these impact on adherence.

Methods

Selection criteria for studies

A review of the literature, published in English since 2000, which is when ART availability occurred in sub-Saharan Africa, was undertaken; and particular attention was given to research conducted in the context of sub-Saharan Africa. Studies reporting on psychosocial factors and how these impact on adherence were sought. To this end, 4 major themes viz: knowledge, experience, disclosure and adherence served as the search engine drivers.

However, given the dearth in the literature in this sub-population, the initial search and inclusion criteria were broadened to include the following: (i) HIV infected and uninfected youth between the ages of <10-<24 years, with the search restricted to studies on impact or links with knowledge around sexual and reproductive health, including HIV, and/or adherence to ART. (ii) Qualitative and quantitative studies, with the latter restricted to studies with virological and immunological outcome measures in relation to adherence only. (iii) Both perinatally and behaviourally infected youth, with the latter also restricted to studies linked with knowledge and/or ability to adhere to ART. (iv) Literature on adolescent health such as development, and sexual and reproductive health (SRH), were included in as far as they were linked or showed impact on knowledge and/or ability to adhere to ART. Insofar as possible the focus was on younger adolescents. Studies were excluded if: the focus was on care-giver input on psychosocial factors and their impact on adherence, for children <15; in the case of behaviourally infected youth, those with a history other than heterosexual HIV transmission.

Search strategy

PubMed, and Google Scholar were searched for published peer and non-peer reviewed papers. Key words for the search criteria included Adolescent, HIV, ART, adherence, disclosure, knowledge, perspectives, attitudes, and stigma. In addition, reference lists of relevant peer-reviewed articles were hand-searched, to ensure comprehensive search of existing literature. Furthermore, literature from sites such as, the World Health Organization (WHO) and the Joint United Nations Programme on HIV AIDS (UNAIDS) were also included, for information on HIV epidemiology and progress thus far. Abstracts were read and all the relevant articles were identified and retrieved, organized thematically, and then summarized.

HIV knowledge among ADLHIV

Given that the youth are the drivers of this epidemic, and most infection is transmitted behaviourally (Wilson et al, 2010; WHO, 2006), knowledge around sexual and reproductive health, including HIV transmission is paramount in prevention strategies. And yet, according to the most recent data, less than 40% of young people have basic information about HIV (WHO, 2009). This assertion has been confirmed by studies on adolescents in low/middle income countries, which also revealed gaps in knowledge around sexual and reproductive health (SRH) issues and HIV transmission (Bakeera-Kitaka et al, 2008; Undie et al, 2007; Jaspán et al, 2009). For instance, a study by Chacko et al (2007), looking at knowledge and perceptions about STI's and pregnancy among Ugandan youth between the ages of 14-18 years, found a general lack of knowledge about the association between HIV/AIDS and pregnancy. Study participants also demonstrated a lack of understanding of the importance of dual protection against HIV transmission and pregnancy through the combination of condom use and contraceptive pill/injection. Similarly, a study by McMannus et al (2008) looking at knowledge, perception and attitudes among Indian girls between ages 14-19 years in Delhi, revealed that 30% of the study participants thought that HIV/AIDS could be cured

and 21% believed that the contraceptive pill was effective in preventing HIV infection. Both these studies, however, only looked at uninfected adolescents ≥ 14 years. To date, there is limited data concerning the young adolescent sub-population, especially in sub-Saharan Africa, regarding knowledge around HIV/AIDS and SRH. Furthermore, knowledge among young ADLHIV remains largely unexplored. However, there is some evidence that even among ADLHIV, gaps and misinformation also exists. A study by Bakeera-Kitaka et al (2008), conducted on HIV+ youth between ages 11-21 in Uganda, examining sexual and reproductive health needs, as well as determinants of sexual risk-taking among young people with HIV, also found knowledge gaps among their study cohort in the areas of reproductive health, HIV transmission, and family planning. In addition, there were misconceptions regarding HIV transmission among the participants, such as: “young children could not get HIV by having sex with an adult” (Bakeera-Kitaka et al, 2008, pg 428). However, according to the study findings, there was some appreciation regarding HIV re-infection and the risks it carried for them in terms of their health (Bakeera-Kitaka et al, 2008). Once more, although the study population age range included young adolescents, the mean and median age of the participants was 16 years.

Misinformation, although considered harmless in certain cases, has a tendency to inform an individual's notion of reality (Chacko et al, 2007). The maxim ‘Knowledge is power’ rings true, especially when it comes to equipping young people to make informed decisions regarding their sexual health (McMannus et al, 2008). Based on the above findings, it can be surmised that in order to stem the tide of high HIV transmission among the youth, and especially secondary transmission by ADLHIV, there is a need to address the SRH knowledge issues while they are pre-pubescent and prior to their sexual debut. A good first step would be by examining how knowledgeable young ADLHIV are regarding SRH issues and HIV transmission and re-infection. This is one of the key aims of the proposed study.

Adolescents' experiences of living with HIV

The effects of the HIV pandemic on children have been substantial, especially in terms of loss of parents and subsequent income. To date, approximately 15 million children have lost either one or both parents to AIDS, resulting in major disruptions in children's lives (Richter et al, 2010). Thus many ADLHIV face the double burden of not only being HIV+, but also, having suffered the loss of one or both parents to AIDS (Strydom and Raath, 2005).

Physical health

In addition, the impact of HIV on growth and development, such as: delayed puberty and stunted growth, (Buonoro et al, 2008; Kekitiinwa et al, 2008; Spiegel and Futterman, 2009) neurological, and language deficits, (Van Rie et al, 2008), and psychiatric illness, commonly anxiety and behavioural disorders (Foster and Fidler, 2010) have been demonstrated. However, findings of neurological and cognitive deficits, were more common among young children <6 years (Van Rie et al, 2008; Bagenda et al, 2006). A long-term prospective study

of HIV+ Ugandan children between ages 6-12yrs, found no significant difference in neurologic and cognitive assessments between this cohort compared to HIV- negative controls (Bagenda et al, 2006). In essence, HIV+ adolescents have normal information processing abilities (Bagenda et al, 2006). This bears remembering, especially considering that the young adolescent should be targeted for behaviour modification interventions, such as SRH education, prior to their sexual debut, in order to achieve effectiveness in stemming the tide of the spread of HIV among the youth and the relevance to the age group in our study.

Globally, studies on chronic illness in adolescents have shown the negative impact of ill-health on the physical, emotional, social and cognitive development of adolescents (Forinde et al, 2008). Hence, for perinatally infected children, the implications are that as they transition into adolescence, they face increasing difficulties in their attempts to negotiate and reach various psychological, biological and cognitive developmental milestones. They have the added burden of having to cope with a health condition that still carries with it a high degree of stigma.

Psychosocial wellbeing

Stigma shapes attitudes and perspectives around HIV and towards those living with HIV. A study done by Ayres et al, (2006), looking at the psychosocial well-being and health care needs of young people between 10-20 years, found stigma to be a recurrent issue that arose among the respondents with regard to their experiences as ADLHIV (Ayres et al, 2006). This points to a need for more community directed intervention programmes to improve attitudes around HIV and those living with the disease. To this end, a study by Stephenson et al (2009), looking into how the community environment shapes the HIV/AIDS attitudes of young people (ages 15-24) in 3 African countries showed that: "Young people with higher knowledge of transmission routes for HIV had more supportive attitudes towards those with HIV" (Stephenson et al, 2009, p.3). Therefore, how adolescents experience HIV, their attitudes and perspectives are significantly shaped by their social and economic environments (Stephenson, 2009).

Very little research has been conducted among adolescents and their perspectives on the issue of stigma and how that affects their experiences, much less among young adolescents. A study by Strydom and Raath (2005), examining the effects of community attitudes found that most ADLHIV experienced rejection and gossip. In addition, a study by Li et al, (2010), on ADLHIV between the ages of 7-15 years, revealed that adolescents viewed HIV as physically and emotionally painful. Furthermore, some reported verbal and physical abuse by peers and care-givers; however, they regarded strong family and friend support systems as positive aspects of their lives (Li et al, 2010). These are some of the limited studies conducted, examining experiences among ADLHIV in sub-Saharan Africa, especially among the younger age group. However, additional research is required in this sub-group of younger adolescents living with HIV. This links well with my study aims to gain insights into their experience of HIV and ART, i.e. attitudes and perceptions and how these impact on their adherence.

4. Disclosure issues among ADLHIV

HIV status disclosure remains one of the most complex and emotive subjects among those affected and infected. The stigma and discrimination associated with HIV, still prevalent even in highly affected communities, adds to the complexities around the issue (Stephenson et al, 2009).

Timing of disclosure

The dilemma of when to disclose and how to disclose and the psychosocial impact the news may have on the child/adolescent are usually what makes it such a daunting task, thus the reluctance on the part of the care-givers, and even health care givers to disclose their status to them (Vujovic et al, 2010). Consequently, studies on disclosure have shown that the number of children and adolescents who are disclosed to, vary. For example, a study by Vaz et al (2010) in the DRC, examining disclosure issues, found that of the 259 HIV+ adolescents between the ages of 8-17 screened, only 8 (3%) had been disclosed to and were thus eligible for study participation. Similarly, a study by Souza et al (2010), examining outcomes of perinatally infected adolescents between 10-19years found that out of a total of 49 study participants, only 31(63%) had been disclosed to. A similar study looking at treatment outcomes of perinatally infected children who had initiated treatment between 2003-2005 found that only 12 (7.9%) knew their status; and of the 12, only 3(25%) of the 9-11year olds and only 5(83%) of the 12-15year olds knew their status(Reddi et al, 2007). Despite these low levels of disclosure to those in the younger age group, the consensus, based on studies done in the United States, is that 8-10 years is considered an acceptable period (Hazra et al, 2010).

Many care-givers are reluctant to disclose to their perinatally infected children. Apart from unease about the infected child's readiness, many cite factors such as: (i) fears that the child might reveal their status to others with negative consequences, such as ostracism, (ii) concerns about how disclosure might affect the parent-child relationship (e.g. anger towards the parent) (iii) and anxiety regarding the child's emotional reaction (Vujovic et al, 2010; Wiener et al, 2007). However, in a systematic review by Wiener et al (2007), looking at research on disclosure rates and correlates and also the psychological impact of disclosure or non-disclosure among perinatally infected adolescents, one study found that of the 99 parent-child dyads interviewed on disclosure, the average age of disclosure was 7.5 years.

With regard to the psychological impact on perinatally infected children and adolescents, the systematic review by Wiener et al (2007), showed that the psychological outcomes following disclosure varied among the different studies. Nonetheless some studies have shown that disclosing a child's HIV+ status to them is beneficial not only to the child but to the care-giver and even the health-care providers looking after these children (Souza et al, 2010). HIV sero-status disclosure has been found to decrease anxiety, depression and behavioural problems (Vujovic et al, 2010 pg 18; Wiener et al, 2007; Gray, 2007). When children have

been disclosed to around age 7 years, in one study, 65% were happy with the timing of their disclosure while 86% felt that disclosure was done by the 'right' person (Wiener et al, 2007).

The process of disclosure

The literature supports disclosure as a process rather than a once-off event (Vujovic et al, 2010; Wiener et al, 2007). However, a study by Vaz et al (2010), looking at experiences of HIV+ adolescents between the ages of 8-17 years, with regard to disclosure revealed that most of the adolescents' experience of disclosure by care-givers was a once-off event rather than a process. The participants in this study reported that little was done to prepare them for the news and little was said afterwards in terms of discussion around the issue. In addition, many were left with unanswered questions about how and why HIV infection occurred and HIV progression. The study reveals that most of the information given was tailored to emphasise the need for good adherence. Furthermore, adherence to medication was also cited by care-givers as the motivation for them to disclose, along with concerns about sexual transmission to potential partners as they got older (Vaz et al, 2010).

Although there is a belief that disclosure is a good strategy to enhance treatment adherence because there is better understanding of the need for ART, and also, trust is built, research on disclosure and adherence is inconclusive (Wiener et al, 2007). On the whole there is a dearth in the literature around the emotional and psychological well-being of children post-disclosure of their HIV status (Vujovic et al, 2010; Vaz et al, 2010). In fact, few studies have looked at circumstances surrounding HIV sero-status disclosure to adolescents, fewer have done so in resource limited settings, and even fewer involving young ADLHIV giving account of their experiences regarding the issue (Vaz et al, 2010). This points to a need for this kind of information to help inform interventions. The proposed study aims to contribute to filling this gap.

5. Adherence and adolescents

As perinatally-infected ADLHIV mature into adulthood, they face a myriad of challenges which have now come to the fore, posing serious dilemmas for ADLHIV, their care-givers and health carers. (Souza, et al, 2010; Strydom and Raath, 2005; Li et al, 2010; Vaz et al, 2010; Nachega et al, 2009; Williams et al, 2006). Maintaining good adherence is a challenge among adolescents as they grow older, as shown in a study looking at predictors of adherence to ART among vertically infected children and adolescents between the ages of 3-18 years. The study revealed a decline in adherence rates with age, and the 15-18 year olds had the worst adherence (Williams et al, 2006). According to established ART guidelines, adherence to ART needs to be >95% consistently to ensure good outcomes in ART (Murphy et al, 2003). A study by Nachega et al (2009) of adolescents between ages 11-19 years showed that ART adherence among adolescents was significantly lower than that of adults, which led to poorer virologic and immunologic outcomes. The literature recommends good adherence to antiretroviral therapy to ensure good virological outcomes and less risk of viral resistance occurring. (Murphy et al, 2003). The latter could significantly limit treatment

options as adolescents mature into adulthood, adding to the individual clinical and public health concerns about this emerging population (Murphy et al, 2003; Wiener et al, 2007).

High pill burden and complex ART regimens make maintaining >95% adherence difficult (Murphy et al, 2003). A study looking at adherence barriers among adolescents with behaviourally acquired HIV cited forgetfulness and changes in daily routine as the most common reasons given by participants for non-adherence (Murphy et al, 2003). Studies conducted among perinatally-infected ADLHIV found similar factors to impact on adherence (Nachega et al, 2009). The study recommends improving ADLHIV's organisational skills as an adherence facilitating strategy, which has been found very effective in children with chronic diseases e.g. Diabetes Mellitus (Murphy et al, 2003). Given the increase in survival of HIV-infected adolescents on ART, it is becoming increasingly important to identify barriers to adherence in this population in order to design appropriate and effective interventions. However, research in this area thus far has been fairly limited, especially in sub-Saharan Africa (Nachega et al, 2009), particularly among young adolescents. In addition, the young ADLHIV's views, knowledge and perspectives on the need for life-long ART remains largely unexplored, thus this study - extending experience of HIV to experience around life-long ART, and how they feel about this as their reality.

Conclusion

There is a real paucity in research data on how the young HIV+ adolescent experiences HIV and ART; what their knowledge, understanding and views are, how socio-cultural influences impact on adherence and finally, how they see the future. Even more importantly, this area of research, on the young, perinatally infected HIV+ adolescents (<15years), remains fairly neglected in sub-Saharan Africa. The focus, so far, has been on adherence in association with virologic outcomes, or care-giver characteristics and influences. Perhaps it's the fact that their age and therefore vulnerability as potential research participants poses serious ethical challenges. That, and also the need for special techniques and provisions upon their inclusion in research, has added to the reluctance to recruiting them as study participants. However, due to the serious individual, clinical and public health implications of possible resistant HIV transmission by these adolescents, there is a need to address the above issues while they are pre-pubescent and prior to their sexual debut.

References

1. Wilson, C.M., Wright, P.F., Safrit, J.T., et al. 2010. Epidemiology of HIV infection and risk in adolescents and youth. *J Acquir Immune Defic Syndr*, 54(1): suppl 1, July 1.
2. World Health Organisation. 2009. *AIDS epidemic update*. Switzerland, Geneva: World Health Organisation/USAID.
3. World Health Organization. 2007. *Helping parents in developing countries improve adolescents' health*. Switzerland, Geneva: World Health Organisation/USAID.
4. Perkins, D. 2000. Understanding adolescence: a time of change. Pennsylvania State University.
5. World Health Organization. 2010. *Towards Universal Access: Scaling up Priority HIV/AIDS Interventions in the Health Sector*. Progress Report 2010. Geneva, Switzerland: World Health Organization. Available at: <http://www.who.int/hiv/pub/2010progressreport/en/>. Accessed 05 February, 2010.
6. Richter, L., Beyrer, C., Kippax, S., et al. 2010. Visioning services for children affected by HIV and AIDS through a family lens. *Journal of the International AIDS Society*, 13(2):1-3, June 23.
7. Ferrand, R., Corbett, E., Wood, R., et al. 2009. AIDS among older children and adolescents in Southern Africa: projecting the time course and magnitude of the epidemic. *Aids*, 23(15):2039–2046.
8. Bakanda, C., Birungi, J., Mwesigwa, R., et al. 2011. Survival of HIV-Infected Adolescents on Antiretroviral Therapy in Uganda: Findings from a Nationally Representative Cohort in Uganda. *PLoS ONE*, 6(4): 1- 6.
9. Davies, M., Keiser, O., Eley, B., et al. 2009. Outcomes of the South African national antiretroviral treatment programme for children: The leDEA Southern Africa collaboration. *S Afric Med J*, 99(10): 730-737, October.
10. Hazra, R., Siberry, G.K., Mofenson, L.M. 2010. Growing up with HIV: children, adolescents, and young adults with perinatally acquired HIV infection. *Annu.Rev.Med*, 61:169-85.
11. Jaspan, H.B., Li, R.J., Johnson, L., Bekker, L-G. 2009. The emerging need for adolescent-focused HIV care in South Africa. *S Afr J HIV Med*, 9-11, December.
12. Souza, E., Santos, N., Valentini, S., et al. 2010. Long-term follow-up outcomes of perinatally HIV-infected adolescents: infection control but school failure. *Journal of tropical pediatrics*, 0(0):1-6.
13. Grey, G. 2009. Adolescent HIV-Cause for concern in Southern Africa. *PLoS Medicine*, 7(2): 1-4, February 2.
14. South Africa. National Department of Health. 2010. *South African National Antiretroviral Treatment Guidelines*. Pretoria. Government Printer.
15. Wiener, L.S., Battles, H.B., Wood, L.V. 2007. A longitudinal study of adolescents with perinatally or transfusion acquired HIV infection: sexual knowledge, risk reduction self-efficacy and sexual behaviour. *AIDS Behav*, 11(3): 471-478, May 1.
16. World Health Organization. 2006. *Preventing HIV/AIDS in young people: A systematic review of the evidence from developing countries*. Switzerland, Geneva: World Health Organization.
17. Bakeera-Kitaka, S., McKellar, M., Snider, C., et al. 2008. Antiretroviral therapy for HIV-1 infected adolescents in Uganda: assessing the impact on growth and sexual maturation. *Pediatr Infect Dis J*, 3:97–104.
18. Undie, C., Crichton, J., Zulu, E. 2007. Metaphors we love by: conceptualizations of sex among people in Malawi. *Afr J Reprod Health*, 11(3): 221–235.

19. Chacko, S., Kipp, W., Laing, L., et al. 2007. Knowledge and perceptions about sexually transmitted diseases and pregnancy: A qualitative study among adolescent student in Uganda. *J Health Popul Nutr*, 25(3):319-327
20. McMannus, A., Dhar, L. 2008. Study of knowledge, perception and attitude of adolescent girls towards STIs/HIV, safer sex and sex education:(a cross sectional survey of urban adolescent school girls in South Delhi, India). *BMC Women's Health*, 8(12): 1-6.
21. Strydom, H., Raath, H. 2005. The psychosocial needs of adolescents affected by HIV/AIDS: A South African story. *International Social Work*, 48(5): 569–580.
22. Buonora, S., Nogueira, S., Pone, M.V., et al. 2008. Growth parameters in HIV-vertically-infected adolescents on antiretroviral therapy in rio de Janeiro, Brazil. *Annals of Tropical Paediatrics*, 28: 59–64.
23. Kekitiinwa, A., Lee, K.J., Walker, A.S., et al. 2008. Differences in factors associated with initial growth, CD4, and viral load responses to ART in HIV-infected children in Kampala, Uganda, and the United Kingdom/Ireland. *J Acquir Immune Defic Syndr*, 49(4):384-392.
24. Spiegel, M.L., Futterman, D.C. 2009. Adolescents and HIV: Prevention and clinical care. *Current HIV/AIDS Reports*, 6:100–107.
25. Van Rie, A., Mupuala, A., Dow, A. 2007. Impact of the HIV/AIDS epidemic on the neurodevelopment of preschool-aged children in Kinshasa, Democratic Republic of the Congo. *Paediatrics*, 122(1):123-128.
26. Foster, C., Fidler, S. 2010. Optimizing antiretroviral therapy in adolescents with perinatally acquired HIV-1 infection. *Expert Rev Anti Infect Ther*, 8(12):1403-1416.
27. Bagenda, D., Nassali, A., Kalyesubula, B.S., et al. 2006. Health, neurologic and cognitive status of HIV-infected, long-surviving, and antiretroviral-naïve Ugandan children. *Paediatrics*, 117(3):729-740.
28. Forinde, U., Posse, E. 2008. “A life on hold”: adolescents’ experiences of stem cell transplantation in a long-term perspective. *J Child Health Care*, 12(4): 301-313.
29. Ayres, J.R., Paiva, V., Franca, I., et al. 2006. Vulnerability, human rights and comprehensive health care needs of young people living with HIV/AIDS. *Am J Public Health*, 96:1001–1006.
30. Stephenson, R. 2009. Community factors shaping HIV-related stigma among young people in three African countries. *AIDS Care*, 21(4): 403–410.
31. Li, R.J., Jaspan, H.B., O'Brien, V., et al. 2010. Positive futures: a qualitative study on the needs of adolescents on antiretroviral therapy in South Africa. *AIDS Care*, 22(6):751-758.
32. Vujovic, M. 2010. *An exploration of disclosure with children living with HIV*: Children's Rights Centre.
33. Vaz, L.M., Eng, E., Maman, S., et al. 2010. Telling children they have HIV: lessons learned from findings of a qualitative study in Sub-Saharan Africa. *AIDS PATIENT CARE and STDs*, 24(4): 247-255.
34. Reddi, A., Leeper, S.C., Grobler, A., et al. 2007. Preliminary outcomes of a paediatric highly active antiretroviral therapy cohort from KwaZulu-Natal, South Africa. *BMC Paediatrics*, 7(13):1-13.
35. Nachega, J.B., Hislop, M., Nguyen, H., et al. 2009. Antiretroviral therapy adherence, virologic and immunologic outcomes in adolescents compared with adults in southern Africa. *J Acquir Immune Defic Syndr*, 51(1):65-71, May 1.
36. Williams, P.L., Storm, D., Montepiedra, G., et al. 2006. Predictors of adherence to antiretroviral medications in children and adolescents with HIV infection. *Paediatrics*, 118(6):1745-1757, November 13.

37. Murphy, D.A., Sarr, M., Durako, S.J., et al. 2003. Barriers to HAART adherence among human immunodeficiency virus-infected adolescents. *Arch Pediatr Adolesc Med*, 157(3):249-255.

Part C: Manuscript

Seeing HIV through the eyes of perinatally infected adolescents living with HIV, on antiretroviral treatment

Pearl Holele, MBChB,^{a,b}, Linda-Gail Bekker, PhD^c, Diane Cooper, PhD^a

^a School of Public Health and Family Medicine, Faculty of Health Sciences, University of Cape Town, Cape Town, South Africa.

^b Western Cape Provincial Department of Health

^c The Desmond Tutu HIV Centre, Institute for Infectious Disease and Molecular Medicine, and the Department of Medicine, Faculty of Health Sciences, University of Cape Town, Cape Town, South Africa.

Correspondence

Pearl Holele

School of Public Health and Family Medicine,
Faculty of Health Sciences,
University of Cape Town,
Anzio Road, Observatory 7925.
Cape Town, South Africa.
Telephone: +27736168134
E-mail Address : skobieh@yahoo.com

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The candidate, Dr Pearl Holele, developed the proposal, oversaw all the field work, and avoided interviewing herself due to a potential “white coat effect”. She analyzed all the data and wrote the manuscript under the supervision for her Masters degree, of Professors Diane Cooper and Linda-Gail Bekker.

No conflict of interest

Abstract

Purpose

As perinatally infected adolescents living with HIV (ADLHIV) grow older and gain a greater sense of independence, disclosure issues and adherence to antiretroviral treatment (ART) have become major concerns. However, research on how adolescents view and cope with these challenges remains limited, especially in Sub-Saharan Africa. We explored ADLHIV's understanding of their infection and its perceived effects on their wellbeing, and ultimately, on their attitude towards life-long adherence to ART.

Methods

A total of 24 perinatally infected male and female ADLHIV, aged 10-15 years, attending an adolescent ART clinic in South Africa, was included in this exploratory study. 12 in-depth qualitative interviews and 2 focus group discussions, were conducted. Qualitative data were analyzed using grounded theory.

Results

Most of the adolescents demonstrated good knowledge and understanding around HIV, how it affects their health and the need for life-long ART. There was general acceptance, but also occasional resentment, anger and frustration regarding HIV and the need for life-long treatment. Nonetheless, their experiences were mostly positive, despite the negative effects of stigma and community attitudes. Knowing that there are others like them, also had a significant impact on how they experienced HIV. Many expressed appreciation for the effects of ART in keeping them healthy, allowing them a normal life and hopefulness about the future.

Conclusion

Despite the challenges of living with HIV, adherence being the major one, most of the young adolescents showed good insights regarding the need for life-long ART and genuine motivation to remain adherent.

Key words: adolescent, HIV, ART, adherence, attitudes and perceptions.

Implications and Contribution

The candidate, Dr Pearl Holele, developed the proposal, oversaw all the field work, and avoided interviewing herself due to a potential “white coat effect”. She analyzed all the data and wrote the manuscript under the supervision for her Masters degree, of Professors Diane Cooper and Linda-Gail Bekker.

University of Cape Town

Introduction

The survival of perinatally infected HIV+ children to adolescence² is increasingly being recognised in sub-Saharan Africa, as the HIV epidemic matures [1-4]. In South Africa, with the largest ART programme in the world to date, approximately 32 000 children under 15 years were noted to be on treatment in 2007 [3]. A South African study looking at treatment outcomes of HIV positive children who access ART under the age of 16 showed 7.7% mortality and 81.1% retention in care, 3 years following ART initiation [3]. This study suggests that similar to the developed world, the first generation of South African perinatally infected children are growing into adolescence with the need for life long antiretroviral therapy [1-2, 5- 6].

Adolescence is characterized by many complex changes, such as cognitive and emotional maturation, usually preceded by physical and sexual maturation [7]. In addition, this developmental phase also includes development of identity, adapting to new social roles and the intricacies of autonomous decision-making. Adolescents are also prone to risk-taking and impulsive behaviour, [7-8]. The latter two developmental challenges render adolescents vulnerable to sexually transmitted infections (STIs), including HIV, and unplanned pregnancies [9-11]. Furthermore, adolescents with chronic diseases such as HIV, in addition to the above-mentioned challenges, are expected to assume greater and greater responsibility for their disease management as they grow older and gain a greater sense of independence. Moreover, they have to make decisions about disclosure to peers and sexual partners, and risk the possibility of rejection and/or stigmatisation, challenges that tend to impact negatively on their adherence [12-13]. In this regard, studies have revealed a decline in adherence rates

² Defined by the WHO as those between 10-19 years.

with age, among adolescents on ART, with the 15-18year olds having the worst adherence [14-15], leading to poor immunologic [15] and virologic outcomes [15,4]. The factors mentioned above pose challenges to successful HIV and ART management in this emergent population, failure of which could have significant individual, clinical and public health impact [13]. For that reason, how adolescents view and cope with these challenges in the worlds that they live in necessitates further studies [13]. In addition, it is important to identify barriers to adherence in this population in order to design appropriate and effective interventions. However, research in this area thus far has been limited, especially in sub-Saharan Africa [15]. Adolescent HIV research has been conducted mostly among adolescents in developed countries, and the majority of those studies have focused on older adolescents (>16yrs) with behaviourally acquired HIV [14].

The primary aim of this study was to attempt to see HIV through the eyes of young (<16 years), perinatally infected adolescents living with HIV (ADLHIV). We explored adolescent understanding of their infection and its perceived effects on their wellbeing. Also, we explored ideas of HIV treatment and the impact of the disease on their social lives and peers. Given the gendered nature of the HIV epidemic in sub-Saharan Africa, gender issues and cultural influences and how these factors impacted on their experience of HIV were also examined.

Methods

Study design

In-depth interview guides, focus groups interview guides and a field-diary were used as data collection tools. The main data collection technique used was in-depth, semi-structured, open-ended interviews. In addition, two focus group interviews were also conducted, on male and female adolescents between the ages of 10-15 years. The participants chosen for focus group interviews were a different sample, to increase the number and diversity of opinions.

Purposive sampling, common in qualitative research entailed sampling those from whom it was felt we would gain the most insights. Written consent to participate, and for the use of an audio-recorder during the interviews, was obtained from the legal guardians of each of the study participants, in addition, assent was obtained from all the study participants. Ethical approval for the study was granted by the University of Cape Town Health Sciences Faculty Human Research and Ethics Committee, in addition, consent to conduct the research was also granted by the Western Cape Provincial Department of Health, the Gugulethu Community Health Centre/Hannan Crusaid Antiretroviral clinic.

The interviews were conducted at the Hannan Crusaid³ antiretroviral (ARV) clinic, in a private counselling room, during the adolescents' clinic visits. Interviews were conducted by a trained fieldworker who was not involved in the adolescents' health care in any way, were in Isi-Xhosa, the first language of respondents, and lasted approximately one hour. Each recorded interview was transcribed and then translated verbatim into English, for ease of analysis.

³ See Appendix 1

A pilot study of five interviews, among respondents not recruited for participation in the actual study, was conducted in same facility by the researcher together with a trained Xhosa-speaking fieldworker, to test the overall feasibility of the data collection methods and the study instruments.

A grounded theory approach was used to analyse the data. During data analysis, there was a search for core meanings, opinions, thoughts, feelings and behaviour of the interviewees. This was followed by an interpretation of the study findings, to demonstrate how themes related to one another and ultimately how concepts answered or responded to the original study questions. Triangulation was used to ensure rigor, by comparing findings with existing data [16]. The researcher did not conduct the interviews due to a possible 'white coat' effect. The research constantly reflected on the data during analysis and consulted others to ensure reflexivity to take due note of her the influence of her role as the attending doctor. Field diary notes were read by the researcher in order to augment the data for analysis.

Results

A total of 24 ADLHIV, between the ages of 10-15 years participated in the study. 12 participants were interviewed, and each focus group consisted of 6 participants. The majority of the participants were female (63%), and the mean age of the participants was 12 years. Results are reported as common to participants in both the individual interviews and the focus groups. Where differences emerged these are specifically noted in the results. Participants' views, perceptions and attitudes did not appear to be influenced by either gender or age, but seemed to arise rather as a consequence of how information was gained and processed. The data is presented according to the major themes that emerged from the interviews and focus group discussions.

1. Knowledge

Most of the participants had some knowledge of HIV prior to knowing their HIV+ status, although for some, the first time they heard about HIV was at home, at the time their disease was disclosed. Sources of information included school, the media, or the health care facility that they attended regularly, i.e. Hannan Crusaid ARV clinic, but for most, most of the information around HIV was acquired primarily from their schools:

“I first heard about it in school, from my teacher. She was saying you get it through blood, when you have sex without a condom, when you touch someone without gloves and when you use someone else’s toothbrush” (part. 2: 10yo F).⁴

On the whole, the participants demonstrated a broadening of their knowledge thereafter. Types of knowledge included: HIV as a life-long infection was commonly understood among most; a few showed an understanding of the difference between HIV and AIDS; another

⁴ Notation for participants in the individual interviews is as follows: participant number: age, and sex, e.g. (participant 2: 10 year old Female, abbreviated in the text as: **part. 2: 10yo F**).

common theme was the importance of and need for anti-retroviral therapy (ART) and its effectiveness against HIV progression. There were some who displayed an understanding of the pathogenesis and transmission, information acquired mostly in their clinic support groups: **“It [HIV] can do something to your body if you don’t take your medication. It can attack “amajoni emzimbeni”⁵ and you can go to stage 4 and get AIDS” (part4: 13yo F [2])⁶.**

For many, the information acquired was accurate. However, a few showed poor knowledge or confusion. One participant seemed confused about HIV and TB and talked about the two conditions interchangeably. In contrast, when asked about general knowledge of peers, most of the participants from the *focus groups* felt that young people in the community and even in schools had limited knowledge around HIV/AIDS. Many of the participants concurred that the support groups that they attended when they came for their clinic visits helped in ensuring that they were better informed, compared to their peers.

The descriptions among the participants in the individual in-depth interviews, when asked to visualize HIV and its effects on the body, varied considerably. Some described HIV as round big and black, or *umoya*⁷, invisible inside the body but harmful. All associated HIV with harmful health effects:

“I picture something that looks strange, that has dirty things on it....well it kills your body cells....it fights with your body cells. HIV is dirty. Your body cells protect you. So HIV brings the virus. Your body cells fight it when you take the medication” (participant 4:13yo F).

⁵ “*Amajoni emzimbeni*”, also sometimes referred to as “soldiers of the body or body cells”, means immune system, a phrase commonly used in the clinic when educating patients on the ill-effects of HIV on the immune system.

⁶ Notation for participants in the focus group discussion are: participant number: age, sex and 1 or 2 for focus grp 1 or 2 participant, e.g. (participant 4: 13 year old Female, abbreviated in the text as: **part4: 13yo F [2]**)

⁷ Umoya is an Isi-Xhosa word meaning the wind/air.

2. Disclosure

Many recall being disclosed to between ages 7-10 years. Most of the participants had their HIV+ status disclosed to them by their care-givers, commonly mothers, at home, and with another relative present. Participants surmised that their caregivers had disclosed their HIV status to them at the time they did: (a) to promote understanding and general tolerance of those living with HIV, or; (b) due to encouragement from health care workers, or; (c) due to curiosity expressed by the participants regarding the need to either continue taking medication for unknown reasons or need for repeated clinic visits. However, in some cases the participants suspected their diagnosis prior to being disclosed to:

“When they were showing treatment on TV, I realized that it looked the same as mine. I suspected that I also had HIV. So I started asking my mom why I was taking this treatment. I wanted her to tell me. I just wanted to know” (part. 1:13yo F).

Participants reported that the information communicated, when they were being disclosed to, emphasized the importance of good adherence. A common theme that also emerged was that many of the care-givers were forthcoming about how the participants acquired their HIV infection. A few were given mixed messages, by initially being told that they have TB.

Participants recalled the moment of diagnosis disclosure with sadness, with many tearful during this part of the study. All the participants described negative reactions, most commonly, emotions were sadness, coupled with shock, fear, disbelief, anxiety that they were going to die, or resignation. In contrast, others, albeit distraught, took comfort in the fact that they were on ART and doing fine. Another participant stated:

“....I went to the bedroom and cried because I was scared, thinking that HIV was going to kill me..... I didn’t know what it was.... I asked why did I get HIV, why? I closed the door and cried...I thought that HIV was on the food” (part 3: 13yo F [1]). Despite the prevailing sad mood in the room, everyone laughed (F/N 1).

There also seemed to be an unspoken element of resentment, especially among some of the younger participants, directed either towards HIV's deleterious health effects and the real possibility of death, or perceived betrayal by those who had kept this illness a secret from them:

"...I was thinking, why my mom never told me [participant very teary at this point]...I asked him [the father who was disclosing to her] why they didn't tell me earlier that I had HIV. He told me that the doctor said I was not supposed to know." (part. 2: 10yo F).

Disclosure to others by the participants was also discussed. Among the group, disclosure to teachers was most acceptable as they were trusted and supportive. One participant disclosed to his teacher because he didn't want the teacher to make a fuss when it was time for him to come to the clinic (F/N 1)⁸. Many of the participants stated that they preferred to disclose only to friends that they know to also be HIV+. Although some participants reported disclosing to trusted friends, many others expressed very strong reservations regarding disclosure to their peers or even close friends. Apart from confidentiality and stigma, fears of rejection and ridicule commonly emerged as the biggest deterrents of disclosure to friends:

"The reason that I don't want to say anything is because it will spread. The whole school will know that I have HIV. I will hear them talking about me. Even in the community, they will then know that someone in the street has HIV. Maybe your mother's friends will say: 'don't play with that child'".

Nonetheless, several of the participants from the focus groups expressed confidence in their friends and felt that their friends would support them if they were aware of their status. However, they wanted their friends to hear about their HIV+ status from them, rather than someone else.

⁸ [F/N 1] stands for Field Notes.

3. Experience of HIV

The issue around community attitudes and the impressions and impact on these ADLHIV was explored in the focus groups. Participants reported that what was commonly encountered:

“.... In the taxis, they just accuse ‘Ow wena une-HIV! [Oh, you have HIV!]'..... (part. 2:11yo F [2]).

Teachers and those in the clinic encouraged them to “live positively”. Participants felt that if the community were better informed, it would be easier to “live positively”; and that perhaps HIV/AIDS education in the community could cause a change in attitudes and perceptions, and lead to less stigmatization of those living with HIV. Some suggested that their clinic counsellors should do some community education (F/N 1).

Most of the participants reported a change in their own feelings as time progressed, becoming more accepting and positive since gaining awareness of their HIV+ status:

“I feel alright, I’m like other children. Because I am also healthy, I take my medication, they make me healthy” (part. 4:13yo F).

What also emerged was the marked difference in the participants’ feelings once they discovered that they were not alone, that there are others their age, that are also living with HIV. Most appeared to take comfort in knowing that there were other adolescents who were going through the same challenges of living with HIV, such as the need for regular pill-taking. Also noted, was the impact that the adolescent clinic the participants attend in particular, appeared to be having on how they experience HIV. They no longer felt isolated:

“It makes me happy. I used to think I was the only one who has HIV. So, I saw at the group [in the clinic] that there are others as well. So it makes me happy. I can talk about anything. We talk about HIV. We talk about what HIV does to people’s

bodies.....we talk at the clinic in a support group. We are all HIV+. You get to talk about stuff bothering you” (part 9:14yo M).

Evident among the participants (who are also fellow clinic attendees) was the existence of trust when around each other. Focus group participants described a particular code of conduct among them to maintain confidentiality, especially outside the clinic in the community, because of the stigma associated with HIV/AIDS.

4. Adherence

Insight regarding adherence was noted to be good among all the participants, in that they all displayed good intentions and a sense of responsibility towards maintaining good treatment adherence, even though they weren't always successful. Most were honest about forgetting to take their treatment occasionally, and stated that they simply forgot. Many barriers to adherence emerged that have been reported elsewhere and are therefore not new insights [12, 15, 19], (see Appendix 2).

Understanding of the value of antiretrovirals was eloquently expressed:

“They are helping to fight the virus and stop it from spreading throughout your body”...and the bad thing about NOT taking ART: “You’ll be letting the virus spread on your body. Even when you don’t take them on time, the virus gets a chance to spread in your body and it does as it pleases. So you need to always take them at the same time every day”. As for the good things about NOT taking ART...to that she answered “None”. (part.1:13yo F). Many felt the same way.

Positive attitudes emanated from the effectiveness of ART that is their reality currently. Reasons most frequently given by participants as their motivation for continued adherence were, the fear of becoming ill and sheer acceptance of their HIV+ status. Some, however, expressed the fear of death from HIV and its health effects, a fear shared by many, coupled with a resentful attitude toward life-long treatment:

“Yhooo, I get angry and sometimes refuse to take pills. I just throw them behind the cupboard....I always drink pills. I’m supposed to be taking them always. So, I want to stop taking pills, but I can’t because it’s here always.....HIV. It’s always in the body” (part.9: 14yo M).

The question of alternatives to ART was dealt with specifically in the focus groups. Participants were asked specifically about alternatives to ARV’s for HIV treatment, e.g. traditional medication, holy water or praying for the virus to go away. Most of them responded by saying *“ayikho”* –“No”. There was consensus that ART was the only effective treatment. Participants also spoke of their hopefulness for the future. This will be dealt with in a separate article (see Appendix 3).

Discussion

This study, to my knowledge the first of its kind in this environment, shows that despite the challenges of living with HIV, adherence being the major one, most of the young adolescents have good insights regarding the need for life-long ART and genuine motivation to remain adherent. Gratifyingly, these adolescents were forthcoming in their ideas and opinions, and showed a depth of understanding of the complexities of HIV/AIDS and its effects on their health. In addition, their views, perceptions and attitudes did not appear to be influenced by either gender or age, but seemed to arise rather as a consequence of how information was gained and processed from various sources such as the media, school and their clinic support groups. This, however, could be a factor of their age, gender becoming a more important variable beyond age 14 years.

Some of the participants demonstrated an understanding of the pathophysiologic processes involving HIV and the effects of ART. Moreover, the adolescents' perceptions and understanding of the effects of ART on HIV progression and on their overall health were good. Many were able to demonstrate an amazing degree of understanding and insight regarding the significance of good ART adherence in relation to HIV progression. The reasons for the need to remain on treatment, and the fact that it's life-long, seemed well understood and generally accepted, even though many did not find it easy or even pleasant. On the whole, the adolescents demonstrated that knowledge of pathophysiology contributed to real understanding of the need for life-long ART. However, since this study did not link responses to actual outcomes, a pronouncement on whether this knowledge translates into better adherence cannot be made. Further studies looking into whether this kind of increased knowledge and pathophysiological understanding enhances adherence are warranted.

Furthermore, these findings are in contrast with findings of previous studies showing knowledge gaps among adolescents, around SRH and HIV [9, 11, 17]. It may be argued however, that the degree of knowledge displayed by these adolescents could be because the majority of the participants subsequently learned more about HIV prevention, transmission, progression and the effects of ART on HIV once they started attending the adolescent clinic and support groups at Hannan Crusaid ARV clinic, where open dialogue and information sharing around these issues are encouraged, under the supervision and guidance of trained youth counsellors. A study by Bagenda et al [18] showed that HIV+ adolescents are inclined to have normal information processing abilities. This assertion tended to be confirmed by the data from this study cohort, with participants demonstrating knowledge and understanding of HIV, especially when they started attending the adolescent support groups. This bears remembering, especially considering that where sexual and reproductive health behaviour modification interventions are concerned, focus needs to shift to include young adolescents, prior to their sexual debut, in order to achieve effectiveness in stemming the tide of the spread of HIV currently evidenced among the youth.

In keeping with other findings [15, 19], but contributing new insights from perinatally infected ADLHIV, participants cited factors such as forgetfulness, busy schedules, interruption of daily routine and stigma as reasons for poor adherence. However, by demonstrating capabilities of not only including pill-taking in their escalating social agendas, but also having clear plans on how they would do so outside the home, especially among peers who don't know their status, suggested good foresight and commitment. Yet, the occasional resentment, anger and frustration at having to take medication all the time needs to be taken into account in counselling. In addition, the appreciation expressed for the effects of

ART in keeping them healthy and allowing them a normal life, as observed by others [20-21], needs to be built on. This is likely to also have contributed to their positive attitude to living with HIV, despite the negative effects of stigma and community attitudes. Moreover, their adolescent clinic support groups seemed to be providing them with an environment that turned what would have been an isolated and burdensome existence into a shared experience and a sense of camaraderie, once they discovered that they were not alone in living with HIV. Positive aspects of taking ART appeared to be strongly linked with their clinic support group experiences. This is in keeping with findings by Li and colleagues [20], on adolescent needs and experiences, in which study participants also cited clinic support groups as one of the positive aspects of living with HIV; which further highlights the need for this intervention as part of the adolescent health services package.

With regard to disclosure, participants' responses illustrate the complexities around paediatric HIV disclosure. Although all the study participants knew their HIV+ sero-status, having been disclosed to by age 10years as per clinic policy, some still felt this was too late. The danger of unduly delaying disclosure is that the child might find out another way, which could have deleterious outcomes, such as broken trust, and may lead to resentment, as demonstrated by some of the study participants. Nonetheless, in keeping with other studies, adolescents valued being informed in a manner that is clear and appropriate [21-22]. In addition, they appreciated family support [20-21] showing the pivotal role of the extended family as support structures, during disclosure, and also as adherence facilitators.

Participants all seemed to share the same dilemmas and fears around trust, stigma and maintaining their friendships; balanced against facing possible rejection and ridicule/ostracism. Even when aware of their status, adolescents' reluctance to discuss the

issue of HIV in the community openly, is shown elsewhere too as a survival strategy against stigmatization [21]. However, despite the above misgivings regarding disclosure, a salient theme that emerged, was the support many felt they would get from their friends if they disclosed to them, and that they would prefer to be the ones who inform their friends of their HIV+ status. Support and guidance for adolescents, in this regard, needs to be looked into.

In terms of socio-cultural influences, all the participants were very clear on the issue of ART as the only effective medication for HIV, and that there is no other alternative. Finally, similar to other findings [20, 21, 23], participants were hopeful about the future, and many expressed desires to get married and have children. However, given the complexities of disclosure, many felt it would be easier to have relationships with partners who are also living with HIV. This is referred to as sero-sorting for partners, and is also shown in other studies.

The limitations of this study were that: (a) the study population is not intended to be representative of the larger HIV+ adolescent population in South Africa. The study participants all attend a Primary level ARV clinic with a special focus on youth-friendly services approach, as such, these adolescents have had very specific youth-friendly inputs, including trained and dedicated youth counselors, and may thus not be representative of other adolescents in general care clinics. (b) the structured support groups, which clearly had a significant impact on the adolescents' experience of living with HIV, do not occur in most facilities with ADLHIV. The strengths of the study were that (a) it gave voice to a largely overlooked sub-group of youth living with HIV, (b) In this setting, these adolescents demonstrated a very good understanding of their illness, and in many cases a well-adjusted attitude to their HIV infection and the need for ART. They also showed good understanding of the reasons why treatment is needed. This indicates that this can be achieved even at primary care level.

Whilst this study indicates a pleasing level of understanding, positive attitude and acceptance among young adolescents born with HIV and now attending clinic for antiretroviral therapy, it doesn't give any indication that this level of understanding translates into better adherence and better outcomes longer term. Further studies, specifically looking at this, are recommended. In addition, data such as this may be used in formulating interventions that could be used in ART and HIV services for adolescents to ensure responsiveness and relevance.

University of Cape Town

References

1. Ferrand R, Corbett E, Wood R, et al. AIDS among older children and adolescents in Southern Africa: projecting the time course and magnitude of the epidemic. *Aids* 2009; 23(15):2039–2046.
2. Bakanda C, Birungi J, Mwesigwa R, Nachega JB, Chan K, et al. Survival of HIV-infected adolescents on antiretroviral therapy in Uganda: findings from a nationally representative cohort in Uganda. *PLoS ONE* 2011; 6(4):1- 6.
3. Davies M, Keiser O, Eley B, et al. Outcomes of the South African national antiretroviral treatment programme for children: The leDEA Southern Africa collaboration. *S Afric Med J* 2009; 99(10):730-737.
4. Nglazi MD, Kranzer K, Holele P, et al. Treatment outcomes in HIV-infected adolescents attending a community-based antiretroviral therapy clinic in South Africa. *BMC Infect Dis* 2012;12(21)
5. Souza E, Santos N, Valentini S, et al. Long-term follow-up outcomes of perinatally HIV-infected adolescents: infection control but school failure. *Journal of tropical pediatrics* 2010;0(0):1-6.
6. Jaspan HB, Li RJ, Johnson L, Bekker L-G. The emerging need for adolescent-focused HIV care in South Africa. *S Afr J HIV Med* 2009; 9-11.
7. Perkins D. Understanding adolescence: a time of change. Pennsylvania State University, Pennsylvania: 2001.
8. Coovadia H, Mantell JE. Adolescents and HIV in Sub-Saharan Africa: A timely issue and missed opportunity. *CID* 2010; 51(7):852-854.
9. McMannus A, Dhar L. Study of knowledge, perception and attitude of adolescent girls towards STIs/HIV, safer sex and sex education: (a cross sectional survey of urban adolescent school girls in South Delhi, India. *BMC Women's Health* 2008; 8(12):1-6.
10. Undie C, Crichton J, Zulu E. Metaphors we love by: conceptualizations of sex among people in Malawi. *Afr J Reprod Health* 2007; 11(3):221–235.
11. Bakeera-Kitaka S, McKellar M, Snider C, et al. Antiretroviral therapy for HIV-1 infected adolescents in Uganda: assessing the impact on growth and sexual maturation. *Pediatr Infect Dis J*. 2008; 3:97–104.
12. Marhefka SL, Koenig LJ, Allison S, et al. Family experiences with paediatric antiretroviral therapy responsibilities, barriers, and strategies for remembering medications. *AIDS Patient Care STDS* 2008; 22(8):637-647.
13. Wiener LS, Battles HB, Wood LV. A longitudinal study of adolescents with perinatally or transfusion acquired HIV infection: Sexual knowledge, risk reduction self-efficacy and sexual behaviour. *AIDS Behav* 2007; 11(3):471-478.
14. Williams PL, Storm D, Montepiedra G, et al. Predictors of adherence to antiretroviral medications in children and adolescents with HIV infection. *Paediatrics* 2006;118(6):1745-1757.
15. Nachega JB, Hislop M, Nguyen H, et al. Antiretroviral therapy adherence, virologic and immunologic outcomes in adolescents compared with adults in southern Africa. *J Acquir Immune Defic Syndr* 2009; 51(1):65-71.
16. Barbour RS. Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *BMJ* 2001; 322:1115-1117.

17. Chacko S, Kipp W, Laing L, et al. Knowledge and perceptions about sexually transmitted diseases and pregnancy: A qualitative study among adolescent student in Uganda. *J Health Popul Nutr* 2007; 25(3):319-327.
18. Bagenda D, Nassali A, Kalyesubula BS, et al. Health, neurologic and cognitive status of HIV-infected, long-surviving, and antiretroviral-naïve Ugandan children. *Paediatrics* 2006; 117(3):729-740.
19. Murphy DA, Sarr M, Durako SJ, et al. Barriers to HAART adherence among human immuno-deficiency virus-infected adolescents. *Arch Paediatr Adolesc Med* 2003; 157:249-255.
20. Li RJ, Jaspán HB, O'Brien V, Rabie H, Cotton MF, Nattrass N. Positive futures: a qualitative study on the needs of adolescents on antiretroviral therapy in South Africa. *AIDS Care* 2010; 22(6):751-758.
21. Ayres JR, Paiva V, Franca I. Vulnerability, human rights and comprehensive health care needs of young people living with HIV/AIDS. *Am J Public Health* 2006; 96:1001–1006.
22. Hazra R, Siberry GK, Mofenson LM. Growing up with HIV: children, adolescents, and young adults with perinatally acquired HIV infection. *Annu.Rev.Med* 2010; 61:169-85.
23. Strydom H, Raath H. The psychosocial needs of adolescents affected by HIV/AIDS: A South African story. *International Social Work* 2005; 48(5):569–580.
24. Bekker L, Myer L, Orrell C, et al. Rapid scale-up of a community-based HIV treatment service: programme performance over 3 consecutive years in Gugulethu, South Africa. *SAMJ* 2006; 96(4):315-322.
25. Augustine J. Serving HIV-Positive youth. *Advocates for Youth*. 2002.

Part D: Appendices

Manuscript appendices

Appendix 1

The study population will come from the Hannan Crusaid adolescent ARV clinic, which is part of the Gugulethu Community Health Centre. Gugulethu is a peri-urban settlement in the **Klipfontein sub-district** of Cape Town, with a combination of formal and informal houses. Out of a total population of ~ 350 000, the unemployment rate is approximately 57%, and about 81% of the population lives in informal housing (Bekker et al, 2006).

The Hannan Crusaid adolescent ARV clinic was launched in 2008, and primarily provides ART to ADLHIV from the Gugulethu area between the ages of 10 and 19 years, as per WHO definition. This service is provided in an adolescent friendly environment that takes into account adolescents' challenging developmental needs in accordance with the Youth Friendly Services initiative by Lovelife (Augustine, 2002). Given that the PMTCT programme coverage in developing countries was only 45% in 2008, (Richter et al, 2010), the majority of the adolescents attending this clinic also have a history of vertical transmission of HIV, and many of them were diagnosed and had their treatment initiated at Red Cross children's hospital. They are initially transferred into the main Hannan Crusaid ARV clinic, which has been providing adult and paediatric ART services to the Gugulethu community since 2002. They are then transferred into the above clinic soon after their 10th birthday, and full disclosure is a pre-condition, prior to the transfer. Doctors, nurses and counselors dedicated to the adolescent clinic facilitate the delivery of care.

Appendix 2

Adherence

The following are some of the adherence barriers and facilitators highlighted by the study participants:

Adherence barriers: many tended to forget when their routine was interrupted, e.g. during school holidays. Other adherence barriers that the participants mentioned included: (i) Interference with social agenda, (ii) Inflexible dosing regimen (iii) ART side effects. What commonly emerged, despite the good intentions, were elements of guilt, resentment and at times rebelliousness, coupled with forgetfulness.

“We were in the E/Cape. I didn’t want to take the pills....I kept throwing them away. When my mom asked me if I took the pills, I’d say yes, when I did not take them but actually threw them away” (part 9:14yo M).

With regard to adherence facilitator: Family support emerged as a major adherence enabler for many of the participants. In addition, participants also mentioned: (i) incorporating pill-

taking into their daily routine, (ii) Use of e.g. cell-phone alarms, (iii) Using specific television programmes, commonly local ‘soap’s’ [soap operas] as reminders. When asked how they would ensure continued adherence when travelling, e.g. on an overnight school outing/camp, one participant said:

“*Kaloku* I’ll take the pills with me, put them in the bag, and then go to the toilet to drink water. No-one will see me” (part 10:15yo F).

Appendix 3

The future

Most of the participants expressed hopefulness about the future, being on ART. Many were intending to finish school. Some expressed hopes of getting married and having families of their own. However, there were some who expressed reservations, especially around having children. Others expressed concerns around relationships. Once again, disclosure, acceptance and support from partners were the specific concerns raised. Quite a few concluded that they would rather have relations with a partner who is also living with HIV:

“I think that HIV will affect my life... I wish I could find someone that will understand that I have HIV and that we can go through things together....I will get someone who has HIV” (part 6: 12yo M [1]).

In-depth interview guides

Archival #	_____
Interviewer	_____
Date of Interview	____/____/____
Interview Start Time	
Interview Stop Time	
Site:	Hannan Crusaid ARV Clinic

Basic Demographic Information

Identifier: Folder number

I am going to ask you some questions about yourself and your experiences as an ADLHIV, some of the questions may be upsetting or may make you feel sad, if that happens, please tell the interviewer, and if you want to stop the interview for a while or completely, that will be ok. If you feel sad and want to talk to someone about it afterwards, we will arrange for you to speak to one of our trained counsellors or the facility social worker.

Before we start, are there any questions that you would like to ask the interviewer before we start?

I would like to start the interview by asking you questions about yourself

Age

Sex

Grade in school

Name of school

Care-giver –parent

Aunt/uncle

Granny

Other

Level of education of care-giver

Language spoken at home

Live in a house or a shack

How many people in the house/shack

Hobbies/interests: *What do you enjoy doing when you're not at school?*

Who is your best friend?

Age at ART initiation {get from patient notes}

Duration on ART {get from patient notes}

Section 1: Knowledge around HIV and attitude towards HIV:

I would like to ask you questions about HIV: what you know about it. It does not matter if you don't know the answers, and for some questions there are no right or wrong answers, we just want to find out what you think and feel.

1. How and where did you hear about HIV for the first time?

Probe: At home

At school

At the clinic

In the street while playing/community

(a) Who did you hear about it from?

Probe: Parent/Care-giver

Peer/Friend

Relative

Health care worker (Dr/Counsellor)

Other

(b) What was being said about it, when you first heard about it?

2. What do you know about HIV?

Probe: *Can draw a picture to describe*

(a) What do you think it looks like?

Probe: *Can draw a picture to describe*

(b) What do you think it does to the body?

Probe: *Can draw a picture to describe*

(c) How do you think it affects your health, overall?

Probe: *Can draw a picture to describe*

Section 2: Questions around disclosure

I would like to ask you questions concerning your HIV status and how you were first informed about your own status

1. How old were you when you found out that you are HIV+?

2. Who told you?

(a) What did they say?

Probe: *Events surrounding disclosure*

Did something happen to prompt it?

Who else was there?

Where you at home, in a private space or not?

3. Who have you spoken to about HIV/ART?

Probe: Family, friends at school or the clinic, Dr, counsellor, other

4. . Do you intend telling your friends or have you told any of your friends already?

Probe: When?

If not, why not?

(b) What are your fears if any, regarding disclosure to friends?

(c) How do you think your friends might treat you when they find out your status?

Section 3: Questions around experience of HIV

I would like you to share with me what it is like living with HIV

1. How did you feel when you were told that you are HIV+?

Probe: Shocked, sad, confused, angry, nothing

(a) How do you feel now that you know?

Probe: relieved, sad, angry, confused

(b) Did you have any suspicions about your status before you were told?

Probe: if so, what made you suspicious?

(c) Did they explain to you how it happened?

2. Since you were informed of your HIV status, have you had an opportunity to discuss the issue with anyone?

Probe: with whom (care-giver, Dr, peers, counsellor)

3. Do you know other young people who are HIV+?

Probe: who?

how did you find out?

how do you feel about those who are HIV+?

4. How did you feel when you realised that you are not the only one living with HIV?

Probe: *Can draw a picture to describe*

Section 4. Questions around adherence

Since you are on ART, I would like to ask you questions around your treatment and how you feel about taking medication all the time

1. Do you know the names of your medication?

Probe: Who taught you?

2. It is very difficult to take your medication all of the time and many people struggle to do so. How much of the time do you take your medication?

(a) Does anyone remind you to take your medication?

(b) Aside from people, do you use other things to remind you to take your medication?

(c) Aside from forgetting, there are other reasons why people don't always take their medication. What are those reasons for you?

(d) Is there anything you can think of that would make it easier for you to take your medication?

3. Can you remember being sick?

If yes, what was that like? What do you remember?

4. How do you feel about taking medication?

(a) Usually people take medication when they are sick and stop when they are well, but you have to take medication even when you are well:

Probe: Do you understand why?

Probe: How does that make you feel?

5. How long do you think you have to take the medication for and why?

(b) How do you feel about taking medication for the next 10 yrs?

(c) How do you feel about taking medication all your life?

6. They say you have to take medication everyday:

Probes: Do you ever forget to take your medication?

What do you think makes you forget?

What do you do when you remember, later?

Who reminds you and how?

When travelling (eg school outing, how do you deal with having to take medication)?

How important do you think it is for you to continue to take your medication?

7. Have you ever thought about stopping to take your medication?

Probes: Why, and if not, why not

(b) Have you actually ever stopped taking your medication?

If the answer is yes then ask the following

Probes: Why did you stop?

How long did you stop taking your medication for?

How did you feel?

(c) What were other people's reactions, e.g. your care-giver, Dr, counsellor

8. What effect do you think the medication has on your health?

Probes: helping? if so how OR
causing harm? if so how, OR
not making a difference, if so how so

9. What do you think the medication is doing to the virus

Probe: *Can Draw a picture to describe*

10. What do you think are the good things about taking medication (all the time)?

11. (a) What do you think are the bad things about taking medication, if any?

11. (b) What are the bad things about not taking medication?

What do you think will happen?

What are the good things about not taking medication?

Section 5. Questions about the future

Since you are on ART, I would like to ask you questions about how you see your future as a young person living with HIV.

1. Where do you see yourself in the next (e.g. 6/12, 1 yr., 5 yrs.)

2. If things were good, what would your life look like

Probes: in terms of your health, school, relationships with friends

2(b) If things were bad what would your life look like

Probes: in terms of your health, school, relationships with friends

3. What do you think you could do to achieve your life being good in (e.g. 6/12, 1 yr., 5 yrs.)

Probes: in terms of adherence to medication, overall health, socially

4. What could others do to help you achieve this?

Probes: Care-givers, health-care givers, friends

Those are all the questions I have got. Is there anything else you would like to tell me about what it is like to have HIV, or what it is like to take medication all the time?

I would like to thank you for agreeing to participate in this study, and thank you especially for sharing your experiences with me. I wish you all the best in your future.

Focus group interview guides

Section 1: Socio-demographic data:

Age
 Gender/Sex
 Grade in school
 Name of school
 Home language
 Residential Area
 Who do you live with

Section 2: Community Attitudes

I would like to ask you questions about what you've heard people in your communities say about HIV and how this has affected you.

1. When and where was the first time you heard about HIV?

Probes: Where: School, Home, Clinic, In the community

When: how long ago
 how old were you?

2. What was said?

Were they saying good things? If so what?
 Were they saying bad things? If so what?
 Anything else?

3. Have you heard other children at school talking about HIV?

Probes: What were they saying?

Were they talking about it in general or were they talking about someone else?

Were they saying good things or bad things?

4. Have you heard other people in the community talking about HIV?

Probes: What were they saying?

Were they talking about it in general or were they talking about someone else?

Were they saying good things or bad things?

5. Have you heard other people in the clinic talking about HIV?

Probes: Was it a Patient, Dr, Counsellor, other

What were they saying?

Were they talking about it in general or were they talking about someone else?

Were they saying good things or bad things?

6. How has it made you feel, when you have heard other people talking about HIV?

Section 3: Knowledge and attitudes among participants

I would like to ask you questions about HIV: what you know about it.

1. Do you know people who are living with HIV?

Probes: Who?

Any relatives, neighbours?

2. What do you think of people who are living with HIV?

Probe: Good/Bad/different from everyone else

3. How do people contract HIV?

Probes: Who gets HIV/what kind of people?

Good/Bad/Anyone

4. How do you think people living with HIV are treated in the community?

(b) How do you think they should be treated?

5. How do you think adolescents living with HIV are treated in the community/ schools?

(b) How do you think they should be treated?

6. What is HIV?

Probe: Describe

7. What effect does HIV have on the body?

Probe: Good/Bad and what makes you think so

8. Since you found out that you are HIV+, how do you feel about being HIV+?

9. You know about HIV because you attend a youth friendly clinic and have been taught about HIV and what it does. Do you think other adolescents know a lot as well?

Probes: Why do you think so? What are they saying? How / where do you think they learn about HIV?

If they are misinformed, how can they be better informed?

10. What do people say happens to those living with HIV?

Probe: Do you agree (why)/disagree (why)?

Section 4: Questions around disclosure

I would like to ask you questions concerning your HIV status and how you were first informed about your own status

1. Have you spoken to anyone about HIV outside of the home?

Probes: Who, when, where and what did you say?

(b) How did they react?

(c) How do you feel now that you have told them?

Probe: has it made things better for you / worse for you?

If you haven't spoken to anyone, why not?

2. What do you think will happen if your friends find out about your status?

Probe: How will that make you feel?

(b) Do you think they would react differently if you heard it from you, or if they found out some other way?

3. If you were to tell someone, who would you tell?

Probes: Why that person?

When?

How?

What would you say?

4. Have you ever brought a friend with you to the clinic?

Probes: If so, who? And why this particular person?

What did you tell them about the clinic?

Do they know your status?

What do you think they will do/say when they find out?

(b) If not, would you consider bringing a friend with you to the clinic?

Section 5: Questions around adherence to ART

Since you are on ART, I would like to ask you questions around your treatment and how you feel about taking medication all the time

1. What have you been told about how long you need to take medication for?

Probes: How do you feel about that?

Do you think you can, even when you are not sick?

Why do you think you need to take medication all the time?

What does it mean to be adherent (what does it mean to you)?

What do you think will happen if you don't take your medication?

2. Do you think the medication is effective?

Probes: If so why/ if not why not?

What effect do you think the medication has on your health/ on your body?

3. It is very difficult to take your medication all the time and many people have problems in doing so. What problems have you had with adherence to your ART regimen?

Probes: What makes it difficult?

What makes it easy?

What do you use as a reminder?

What else would help you to take your medication?

4. What, if anything, do you think will happen if you don't take your medication?

5. Do you think there are other things that will help or cause harm other than ART?

6. What advice or suggestions would you give to others who may be experiencing any problems with?

being an ADLHIV or

adhering to their treatment regimen?

7. What advice or suggestions would you give to others about what they can expect with?

being an ADLHIV?

with adhering to their treatment regimen?

Section 6: The future: *Note gender differences*

1. How do you see your future living with HIV?

2. How do you see your future being on ART for life?

Probes: Finishing school

Remaining healthy

Jobs

For 13-15yr olds: Dating

Getting married

Having children

Disclosure to partner

Note any gender differences on these issues specifically

Those are all the questions I have got. Is there anything else any of you would like to tell me about what it is like to have HIV, or what it is like to take medication all the time?

I would like to thank you all for agreeing to participate in this study, and thank you especially for sharing your experiences with me. I wish you all the best in your future.

University of Cape Town

Consent forms

FORM A: Parental Consent

University of Cape Town
 CONSENT TO PARTICIPATE IN RESEARCH

Study title: Seeing HIV through the eyes of perinatally infected adolescents living with HIV, on antiretroviral treatment.

Dr Pearl Holele from the school of Public Health and Family Medicine is conducting a study on the above topic. This will include examining how young, asymptomatic adolescents living with HIV experience HIV, and how these experiences ultimately impact on their adherence to anti-retroviral treatment. This research study is conducted for post-graduate degree purposes.

The participation of your adolescent in either the one-on-one interviews or focus group discussions that will be conducted for this study will be highly appreciated.

The Isi-Xhosa version of this form is will be read out to you as the parent/legal guardian of the participating adolescent. If you give your permission for your adolescent to take part in this research study, you will then be asked to sign it prior to the interview. Before you sign the consent form, we will ask you a few questions to ensure that you understand the information given on the consent form. You will be given a copy of the consent form, and the other copy will be kept with the interview material for our records.

Purpose of the study

To talk to adolescents between the ages of 10 and 15yrs, who have been living with HIV since birth, to find out how they experience HIV. In other words, what their understanding of their illness is, their feelings and attitudes around living with HIV, and how they think HIV affects their bodies and self-image. Also, what their understanding is of the need to take lifelong antiretroviral treatment.

Your adolescent's part in the study

If you give your permission for your adolescent to take part in this research study, a trained fieldworker will ask your adolescent to respond to a series of questions around what they know and understand about HIV and the need for lifelong antiretroviral treatment. They will also be asked questions around stigma, disclosure issues and how they see the future as individuals living with HIV. The fieldworker will either speak to them individually (i.e. a one-on-one interview) or as part of a group of 6 adolescents (i.e. a focus group discussion). Each interview or focus group discussion will last for about an hour. The interview or focus group discussion will be captured on an audio-recorder with your permission. In addition, a youth counselor known to you and your adolescent will be present to facilitate the process.

Potential risks for the adolescent

HIV in itself is a fairly sensitive subject and the adolescents who are asked to take part in the study are still fairly young. The adolescents may therefore find speaking about HIV and how it affects their lives upsetting, because it may remind them of painful experiences that they've had. Your adolescent will be informed that they do not have to answer any particular question or discuss any subject or issue that they are not comfortable discussing. After the interview, your adolescent will be referred to a trained youth counselor or social worker for debriefing if the need arises.

Participation and withdrawal

Your adolescent does not have to take part in the study, even if you as the parent/legal guardian have given your consent for them to do so. In addition, even though you have signed and consented to have your adolescent take part in the study, you have a right to withdraw your adolescent's participation in the study at any time. Also, your adolescent has the right to discontinue their participation in the study at any time during this process. If you choose not to allow your adolescent to take part in the study or if you withdraw their participation in the study once you have agreed to have them participate, it will not affect the care that they receive at the clinic or how the people who work at the clinic treat them or you.

Potential benefits of the research

Your adolescent will not benefit directly from taking part in this study; however, by doing this study, we hope to gain a better understanding of the impact of HIV on young adolescents

who are living with HIV and are on antiretroviral treatment. It is hoped that the study findings will be used to influence policy on the management of adolescent health, to make the services more adolescent friendly.

Confidentiality and Anonymity

If you give your consent for your adolescent to take part in this study, be assured of the following:

- (a) They will be given a code number
- (b) Their name and all other personal information will be stored under that code number, to ensure anonymity
- (c) All their views, feelings, opinions, etc. will be used for research purposes only, and will only be disclosed with their permission
- (d) The information obtained from your adolescent will only be available to the researcher and fieldworker, and will be kept in a safe place at all times.

Confidentiality in Focus Groups (only applicable to those participating in focus group discussions)

If you give your consent for your adolescent to take part in a focus group discussion, they will form part of a group of 6 adolescents in total. In addition to the above measures, we will also ask the 6 focus group members not to discuss information shared during the focus group discussion with people that were not part of the focus group. However, please be aware that in this instance, confidentiality cannot be guaranteed and is dependent on each focus group members adhering to this agreement.

Researcher medico-legal obligations

Researchers working with children have certain legal obligations. This is to ensure that those children that are found to be in need of care or are in danger, are reported to the appropriate authorities, so that those children can get the necessary help. Thus, because of these obligations, the things that your adolescent tells us during the interview regarding their behaviour will be private unless it turns out that they are in a situation where they are being hurt or taken advantage of by someone; or conversely, if they are in danger of harming themselves or another person.

For instance we **Will** inform the relevant authorities, but **not** you:

- (a) If it turns out that they are being abused or neglected
- (b) If it turns out that they have been the victim of a sexual offense, e.g. rape
- (c) If it turns out that they are in danger of harming themselves or others
- (d) If it turns out that they are not attending school and they are under the age of 15.

If any of the above is unearthed during the interviews, not only will the adolescent be informed of the necessary steps to be taken, but they will also be provided with the necessary and appropriate support. In addition, we will assist in informing you as parent/legal guardian, so that they can get you the support that they need to deal with the situation.

Payment for taking part

All study participants and their parents/legal guardians will be offered taxi-fare for their trip to and from the clinic and also some refreshments during the interview sessions.

Identification of investigator

If you have any questions or concerns about the research, please feel free to contact the researcher

Pearl Holele

Telephone: 0736168134

Email: skobieh@yahoo.com

Rights of research subjects

If you have questions or concerns about your rights or the rights of your adolescent while they are taking part in the study, there is a team of researchers and doctors who are there to make sure that the research is done in a way that is safe and proper for those who have been asked to take part in the study. They can be contacted at: The Research Office, Faculty of Health Sciences at the University of Cape Town on 021 650 4015.

Questions to ensure clarity

If you give your permission for your adolescent to take part in this research study, we would like to ask you a few questions to ensure that you understood the information given on the consent form, before you sign it:

- (a) Is there anything more that you would like to know?
- (b) Could you explain to me what we are going to do and what your adolescent would need to do if they agree to participate in the study
- (c) What worries you most if you were to choose to have your adolescent participate in the study?
- (d) How long will the interview or focus group discussion last?
- (e) Do you know who to contact if you have a problem or question about the study?

SIGNATURES

I _____ (name of parent/legal guardian) declare that I have read and understood the above information and I was given adequate time to consider my child's participation in the study and my questions were answered satisfactorily. I hereby consent to the participation of my child in this study.

_____ (Signature) _____ Date.

Relationship to the adolescent: _____

Field worker

I declare that I read this document to the participant's mother, in Isi-Xhosa. I have tried to answer her questions to the best of my knowledge.

Date: _____ Signature of Fieldworker: _____

Contact details of fieldworker:

FORM B: Adolescent Assent

University of Cape Town
CONSENT TO PARTICIPATE IN RESEARCH

Study title: Seeing HIV through the eyes of perinatally infected adolescents living with HIV, on antiretroviral treatment.

Dr Pearl Holele from the school of Public Health and Family Medicine is conducting a study on the above topic. This will include examining how young, asymptomatic adolescents living with HIV experience HIV, and how these experiences ultimately impact on their adherence to anti-retroviral treatment. This research study is conducted for post-graduate degree purposes.

We would like to invite you, with your parent/legal guardian's permission, to participate in the one-on-one interviews or focus group discussions which will be conducted for the above study. You are allowed to take some time to decide whether or not you would like to be included, or to speak to someone you trust such as your parent or counsellor to help you in your decision.

In order to obtain your assent, the content of the assent form will be read and explained to you in Isi-Xhosa, to ensure that you understand what the process entails and what is expected of you. If you choose not to give your assent, you will not be included in the study, even if your parent/legal guardian has consented to your participation. Before you sign the assent form, we will ask you a few questions to ensure that you understand the information given on the assent form. A copy of the assent is to be kept by your consenting parent/legal guardian, and the other copy is to be kept with the interview material for our records.

What is the study about

We would like to talk to adolescents between the ages of 10 and 15yrs, who have been living with HIV since birth, like you. Our aim is to find out how you and your peers experience HIV. In other words, what your understanding of your illness is, your feelings and attitudes

around living with HIV, and how you think HIV affects your bodies and self-image. Also, what your understanding is of the need to take lifelong antiretroviral treatment.

What is expected of me

If you agree to take part in this research study, a trained fieldworker will ask you some questions. She will either speak to you alone, in the form of an interview, or in the form of a group discussion, with 5 other adolescents. The questions will be about how much you know and understand about HIV; Taking antiretroviral treatment; Stigma, disclosure issues and how you see the future as an adolescent living with HIV. The interview will last for about an hour, it will be captured on an audio-recorder with your permission, and a youth counselor that you are familiar with will be present to facilitate the process.

What are the potential risks

HIV in itself is a fairly sensitive subject and because you are still fairly young, you may therefore find speaking about HIV and how it affects your life upsetting, because it may remind you of painful experiences that you've had. Please be assured that you do not have to answer any particular question or discuss any subject or issue that you are not comfortable discussing. After the interview, you will be referred to a trained youth counselor or social worker for debriefing if the need arises.

Participation and withdrawal

You do not have to agree to take part in the study, even if your parent/legal guardian has given their permission for you to do so. Also, even though you have agreed take part in the study, you have the right to withdraw from participating in the study at any time during this process. If you choose not to take part in the study or if you withdraw once you have agreed to participate, it will not affect the care that you receive at the clinic or how the people who work at the clinic treat you.

Potential benefits of the research

You will not benefit directly from taking part in this study. However, we hope that the study will give us a better understanding of what it is like living with HIV and taking antiretroviral treatment as a young adolescent. We hope that the information we get from doing the study

will be used to come up with health programmes that will deal with the concerns and challenges highlighted in the study findings, which will result in services that are more adolescent friendly.

Confidentiality and Anonymity

If you agree to take part in this study, be assured of the following:

- (a) You will be given a code number
- (b) Your name and all other personal information will be stored under that code number, to ensure anonymity
- (c) All your views, feelings, opinions, etc. will be used for research purposes only, and will only be disclosed with your permission
- (d) The information obtained from you will only be available to the researcher and fieldworker, and will be kept in a safe place at all times.

Confidentiality in Focus Groups (only applicable to those participating in focus group discussions)

If you agree to participate in a focus group discussion then 6 of you will gather together and answer questions, sharing your ideas, feelings and opinions about living with HIV and taking antiretroviral treatment. In order to ensure privacy, we will also ask each of you in the group to commit to not discuss information shared during the focus group discussion with people that were not part of the focus group. However, please be aware that in this instance confidentiality cannot be guaranteed and is dependent on each member of the focus group adhering to this agreement.

Researcher medico-legal obligations

Researchers working with children have certain legal obligations. This is to ensure that those children that are found to be in need of care or are in danger, are reported to the appropriate authorities, so that those children can get the necessary help. Thus, because of these obligations, the things that you tell us during the interview regarding your behaviour will be private unless it turns out that you are in a situation where you are being hurt or taken advantage of by someone; or conversely, if you are in danger of harming yourself or another person.

For instance we Will be obliged to inform authorities, but **not** your parents:

- (a) If it turns out that you are being abused or neglected

- (b) If it turns out that you have been the victim of a sexual offense, e.g. rape
- (c) If it turns out that you are in danger of harming yourself or others
- (d) If it turns out that you are not attending school and you are under the age of 15.

If any of the above is unearthed during the interviews, not only will you be informed of the necessary steps to be taken, but you will also be provided with the necessary and appropriate support. In addition, we will assist in informing your parent/legal guardian, so that they can give you the support you need to deal with the situation.

Payment for participation

All study participants and their parents/legal guardians will be offered taxi-fare for their trip to and from the clinic and also some refreshments during the interview sessions.

Identification of investigator

If you have any questions or concerns about the research, please feel free to contact the researcher

Pearl Holele

Telephone: 0736168134

Email: skobieh@yahoo.com

Rights of research subjects

If you have questions or concerns about your rights there is a team of researchers and doctors who are there to make sure that the research is done in a way that is safe and proper for those who have been asked to take part in the study. They can be contacted at: The Research Office, Faculty of Health Sciences at the University of Cape Town on 021 650 4015.

Questions to ensure clarity

If you agree to take part in this research study, we would like to ask you a few questions to make sure that you understood the information given on the assent form, before you sign it:

- (a) Is there anything more that you would like to know?
- (b) Could you explain to me what we are going to do and what you would need to do if you agree to participate in the study
- (c) What worries you most if you were to choose to participate in the study?
- (d) How long will the interview or focus group discussion last?
- (e) Do you know who to contact if you have a problem or question about the study?

SIGNATURES**CONSENT:**

I _____ (name of parent/legal guardian) declare that I have read and understood the above information and I was given adequate time to consider my child's participation in the study and my questions were answered satisfactorily. I hereby consent to the participation of my child in this study.

_____ (Signature) _____ Date.

ASSENT:

I _____ (name of adolescent) declare that the information about this study has been explained to me, and I understand what the study is about and my role once I agree to take part in the study. I agree to take part in the study.

FIELD WORKER

I declare that I read and explained this document to the participant, in Isi-Xhosa. I have tried to answer their questions to the best of my knowledge.

Date:

Signature Fieldworker:

Contact details fieldworker:

Date:

Signature participant:

Letter of approval from Research Ethics Committee



UNIVERSITY OF CAPE TOWN

Health Sciences Faculty
Human Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
e-mail: shuretta.thomas@uct.ac.za

18 August 2011

HREC REF: 243/2011

Dr P Holele
c/o Prof D Cooper
Public Health & Family Medicine

Dear Dr Holele

PROJECT TITLE: SEEING HIV THROUGH THE EYES OF PERINATALY INFECTED ADOLESCENTS LIVING WITH HIV, ON ANTIRETROVIRAL TREATMENT.

Thank you for addressing the issues raised by the Faculty of Health Sciences Human Research Ethics Committee in your letter dated 12 August 2011.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year till the 28 August 2012.

Please submit a progress form, using the standardised Annual Report Form (FHS016), if the study continues beyond the approval period. Please submit a Standard Closure form (FHS010) if the study is completed within the approval period.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the HREC. REF in all your correspondence.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

s.thomas

Western Cape Department of Health

07/11/2011 12:38 0214899995

FINANCE

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DEPARTMENT OF HEALTH

Provincial Government of the Western Cape

STRATEGY & HEALTH SUPPORT

healthres@pwg.gov.za
Tel: +27 21 483 9907, Fax: +27 21 483 9995
1st Floor, Nelson Rode House, 8 Riebeeck Street, Cape Town, 8001
www.westerncape.gov.za

REFERENCE: RP 10/2011
ENQUIRIES: Dr V Appiah - Baiden

c/o Dr Cooper
Dept of Public Health and Family Medicine
University of Cape Town
OBSERVATORY

For attention: Dr Deed Hlelele, Professor Dr Cooper Professor Linda Gail Bekker

Re: SEEING HIV THROUGH THE EYES OF PERINATALLY INFECTED ADOLESCENTS LIVING WITH HIV, ON ANTIRETROVIRAL TREATMENT

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research. Please contact the following people to assist you with any further enquiries.

Gugulethu CHC: Hannan Gersold ARV Clinic Dr J Claassen (021) 370 5007

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final report within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (healthres@pwg.gov.za).
3. The reference number above should be quoted in all future correspondence.

We look forward to hearing from you.

Yours sincerely

DR J CLAASSEN
DIRECTOR: HEALTH IMPACT ASSESSMENT
DATE: 7/11/2011

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Instruction for Author of Journal of Adolescent Health

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Editor

Charles E. Irwin, Jr., M.D., Editor-in-Chief
Tor D. Berg, Managing Editor
Phone: 415-502-1373
E-mail: tor.berg@ucsf.edu
Editorial Office, *Journal of Adolescent Health*
University of California, San Francisco
Research and Policy Center for Childhood & Adolescence
3333 California Street, Suite 245
San Francisco, California 94118-6210

Publisher

Andrea Boccelli, Publisher
Phone: 215-239-3713
E-mail: a.boccelli@elsevier.com Elsevier
1600 John F. Kennedy Blvd, Suite 1800
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Editorial Policies

General Information

The Journal of Adolescent Health publishes Original Articles, Adolescent Health Briefs, Review Articles, Clinical Observations, and Letters to the Editor.

Duplicate/Prior/Overlapping Publication or Submission

Manuscripts are submitted for review with the understanding that they are being submitted only to the *Journal of Adolescent Health*. The *Journal* will not consider for review any manuscript that has been published elsewhere, that is currently under consideration by another publication, or that is in press. Poster and platform presentations and abstracts are not considered duplicate publications, but should be noted in the manuscript's cover letter and Acknowledgements section of the manuscript.

If the submitted manuscript contains data that have been previously published, is in press, or is currently under review by another publication in any format, the authors are required to submit a reprint of the published article or a copy of the other manuscript to the Editor-in-Chief with a clarification of the overlap and a justification for consideration of the current submitted manuscript.

The Editors encourage authors to report fully the complete findings of their studies. The

editors recognize that large and longitudinal datasets often result in multiple publications both on different topics and on the same topics across the span of development. Therefore, it is the authors' strict responsibility both to notify the editors of the existence of multiple manuscripts arising from the same study and to cross-reference all those that are relevant.

Manuscripts accepted for peer review may be submitted to the iThenticate plagiarism checker. iThenticate compares a given manuscript to a broad range of published and in-press materials, returning a similarity report, which the editors will then examine for potential instances of plagiarism and self-plagiarism.

Failure to disclose multiple or duplicate manuscripts may result in censure by the relevant journals and written notification of the appropriate officials at the authors' academic institutions.

Authorship Criteria

As a condition of authorship, all listed authors must have seen the final draft of the manuscript, approve of its submission to the *Journal of Adolescent Health*, and be willing to take responsibility for it in its entirety.

For manuscript's accepted for peer review, a signed Statement of Authorship will be requested from each named author. The Journal's Statement can be downloaded in PDF format [here](#). We prefer an electronic copy of the statement: please electronically sign the PDF using Acrobat or print the PDF, sign it by hand, and scan it. We can also receive statements by fax at (415) 476-6106, though it may delay processing of your manuscript.

If there are concerns about how all persons listed as authors meet the criteria for authorship according to the Uniform Requirements for Manuscripts Submitted to Biomedical Journals: Writing and Editing for Biomedical Publication available at <http://www.icmje.org/>, we will request further information from the corresponding author and, if necessary, request written documentation of each person's work on the report.

The names, along with any conflicts of interest, funding sources, and industry-relation, of persons who have contributed substantially to a study but who do not fulfill the criteria for authorship are to be listed in the Acknowledgments section. This section should include individuals who provided any writing, editorial, statistical assistance, etc.

Ethical Approval of Studies, Informed Consent, and Identifying Details

Studies of human subjects must document that approval was received from the appropriate institutional review board. When reporting experiments utilizing human subjects, it must be stated in writing, in the Methods section, that the Institution's Committee on Human Subjects or its equivalent has approved the protocol. The protocol for obtaining informed consent should be briefly stated in the manuscript. The Editor-in-Chief may require additional information to clarify the safeguards about the procedures used to obtain informed consent. Within the United States, the authors should verify compliance with the Health Insurance Portability and Accountability Act of 1996 (HIPPA) prior to submission. When reporting experiments on animal subjects, it must be stated that the institution's animal care and use committee has approved the protocol.

Authors must immediately disclose to the *Journal of Adolescent Health* in writing the existence of any investigation or claim related to the manuscript with respect to the use of

human or animal subjects that may be initiated by an institutional, regulatory, or official body at any time, including investigations or claims arising subsequent to manuscript submission, approval or publication.

Clinical Trials Registration

In order to foster a comprehensive, publicly available database of clinical trials, journals increasingly are requiring the registration of clinical trials. At this time, registration is not required for submission or publication in the *Journal of Adolescent Health*. However, the Editors strongly recommend registration of clinical trials in an appropriate registry. Please provide the site of registration and the registration number on the title page.

One such registry is ClinicalTrials.gov, a service of the U.S. National Institutes of Health, at <http://www.clinicaltrials.gov/>. A number of other registries are available.

Conflict of Interest/Disclosure Policy

According to the World Association of Medical Editors (WAME):

"...a conflict of interest (competing interest) is some fact known to a participant in the publication process that if revealed later, would make a reasonable reader feel misled or deceived (or an author, reviewer, or editor feel defensive). Conflicts of interest may influence the judgment of authors, reviewers, and editors; these conflicts often are not immediately apparent to others. They may be personal, commercial, political, academic, or financial. Financial interests may include employment, research funding (received or pending), stock or share ownership, patents, payment for lectures or travel, consultancies, nonfinancial support, or any fiduciary interest in the company. The perception of a conflict of interest is nearly as important as an actual conflict, since both erode trust."

Authors are required to disclose on the title page of the initial manuscript any potential, perceived, or real conflict of interest. Authors must describe the role of the study sponsor(s), if any, in 1) study design; 2) the collection, analysis, and interpretation of data; 3) the writing of the report; and 4) the decision to submit the manuscript for publication. Authors should include statements even when the sponsor had no involvement in the above matters. Authors should also state who wrote the first draft of the manuscript and whether an honorarium, grant, or other form of payment was given to anyone to produce the manuscript. If the manuscript is accepted for publication, the disclosure statements may be published.

Fast-Tracking for Critical Issues in Adolescent Health and Medicine : *The Journal of Adolescent Health* has developed a fast-tracking system in order to facilitate and encourage the submission of high quality manuscripts with documented findings that may change the content of clinical practice or assist with the national and/or international dialogue about critical issues affecting adolescents and young adults. Manuscripts accepted for a fast-track review will be forwarded to two reviewers from our Editorial Board, who are given two weeks to conduct an expedited review. The *Journal* will notify authors of the outcome of the review within three weeks of submission. If the review is favorable, fast-track authors will be asked to complete any necessary revisions within two weeks.

Upon acceptance, fast-track manuscripts are prioritized for publication, and should appear in print within two months.

Fast tracking is a rare event intended for high-priority findings and should not be viewed

simply as a mechanism for an expedited review. The article should be prepared in the same manner as an Original Article.

The Editorial Process

Acceptance for Review

Manuscripts submitted to the *Journal of Adolescent Health* are reviewed internally for interest and relevance. Approximately half of all submitted manuscripts are returned to the authors without full peer review. That decision is made quickly, within two weeks of submission

Peer review and Decision

Manuscripts accepted for peer review are sent to three external reviewers. Reviewers are anonymous; authors' names are revealed. The *Journal's* goal is to complete peer review and reach a decision within seven weeks of submission.

Manuscripts will either be declined based on reviewer comments or referred back to the authors for revision. This is an invitation to present the best possible paper for further review; it is not an acceptance.

Authors are asked to complete revisions within 30 days. If the authors do not respond within 30 days, the editors may decline to consider the revision. The editors reciprocate by providing a final decision quickly upon receipt of the revision.

Acceptance for Publication

All manuscripts accepted for publication will require a written assignment of the copyright from the author(s) to the Society for Adolescent Health and Medicine. Elsevier Inc. will maintain all records of the copyright for the Society for Adolescent Health and Medicine. No part of the published material may be reproduced elsewhere without written permission from the publisher.

Authors will receive typeset galley proofs via e-mail from the *Journal's* issue manager at Elsevier. Proofs should arrive approximately four to six weeks following acceptance.

The article will be published in the print edition of the *Journal* approximately five to seven months after acceptance.

Articles Online First

The Journal of Adolescent Health publishes articles online ahead of print publication in the Articles Online First section of our web site. Articles are published online approximately four to six weeks following the galley proofs. The online article is identical to the version subsequently published in the print journal, and is citable by the digital object identifier (DOI) assigned at the time of online publication.

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Until the time of publication on the *Journal of Adolescent Health's* website, it is a violation of

the copyright agreement to disclose the findings of an accepted manuscript to the media or the public. If you require an embargo date for your article, please contact the *Journal's* editorial office.

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Manuscript Preparation

General information

Manuscripts are submitted to the journal electronically. Manuscript documents must comply with layout and length requirements outlined below. All accepted manuscripts may be subject to editing and revision by the editors and their agents. Authors should take care to avoid redundancy within the text and between the tables, figures, and text. Due to page limitations, the editors may decide that figures, appendices, tables, acknowledgements, and other materials be published online only and referenced in the print edition of the *Journal*.

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Manuscripts must be submitted online via the Elsevier Editorial System (EES). To access EES, go to <http://ees.elsevier.com/jah/> and register as a new user. You will be guided stepwise through the creation and uploading of the various files and data. Once the uploading is done, the system automatically generates an electronic (PDF) proof, which is then used for reviewing. All correspondence regarding submitted manuscripts will be handled via e-mail through EES.

For the purposes of EES, a manuscript submission consists of a minimum of two distinct files: a Cover Letter, and the Manuscript itself including the Title Page (with any Acknowledgements) and the Abstract. EES accepts files from a broad range of word processing applications. Both files should be set in 12-point double-spaced type and all pages should be numbered consecutively). The file should follow the general instructions on style/arrangement, and, in particular, the reference style.

In addition, Tables and Figures should be included as separate and individual files.

If Electronic submission is not possible, please contact Mr. Tor Berg, the managing editor at tor.berg@ucsf.edu, or by phone at 415-502-1373 or by mail at Editorial Office, *Journal of Adolescent Health*, University of California, San Francisco, Research and Policy Center for Childhood and Adolescence, 3333 California Street, Suite 245, San Francisco, California 94118.

Cover Letter

A Cover Letter must accompany all submissions. The Cover Letter should describe the manuscript's unique contribution and provide the following information in accordance with the Uniform Requirements for Manuscripts Submitted to Biomedical Journals: Writing and Editing for Biomedical Publication available at <http://www.icmje.org/>

- Disclosure of any prior publications or submissions with any overlapping information, including Methods, or a statement that there are no prior publications or submissions with any overlapping information;
- A statement that the work is not and will not be submitted to any other journal while under consideration by *The Journal of Adolescent Health*;
- A statement of any potential conflict of interest, real or perceived, the role of the study sponsor, and additional disclosures, if any; potential conflicts must also appear on the Title Page.

Title Page/Acknowledgements

The title page should contain a concise but informative title (titles are limited to 150 characters). Include the full names of all authors, as well as the highest academic degrees and the departmental and institutional affiliation of each. Please note that the *Journal* does not list fellowships of professional or certifying organizations as credentials. Relevant sources of financial support and potential conflicts of interest should be reported for all authors (see the *Journal's* Conflict of Interest/Disclosure Policy).

Named authors must have made a significant contribution to the manuscript (see the *Journal's* Authorship Criteria). A list of more than 6 authors should be specifically justified in the manuscript's cover letter.

One author must be designated as the corresponding author, and should provide a complete postal address, telephone number, fax number, and e-mail address. The corresponding author will conduct all correspondence with the Editorial Office on behalf of the other authors. If the manuscript is accepted, page proofs and reprint order forms will be sent to the corresponding of author.

The title page should also include an Acknowledgements section, listing any sources of support such as grants, equipment, or drugs; and any acknowledgements of persons who have made a substantive contribution to the study. Authors should obtain written permission from anyone that they wish to list in the Acknowledgement section. The corresponding author must also affirm that he or she has listed everyone who contributed significantly to the work in the Acknowledgements. Previous oral or poster presentations at local, regional, national or international meetings should be reported here.

Abstract and Key Words

The abstract should be provided in a structured table format with the following bolded headings: Purpose, Methods, Results and Conclusions. Emphasis should be placed on new and important aspects of the study or observations. Only common and approved abbreviations are acceptable. Three to 10 key words or short phrases should be identified and placed below the abstract. These key words will be used to assist indexers in cross-indexing the article and will be published with the abstract. For this, terms from the Medical Subject Headings list in the Index Medicus should be used whenever possible.

Manuscript

The text of original articles and briefs should usually - but not necessarily - be divided into the following sections: **Introduction**, **Methods**, **Results**, and **Discussion**. Additionally, the *Journal* requests an **Implications and Contribution** summary statement.

Implications and Contribution: In addition to the abstract, please include a summary statement at the beginning of your manuscript. This summary should be no more than 50 words in length and should describe the significance of your study's findings and its contribution to the literature in plain language. These summaries appear on the published articles and in various digests and newsletters.

Introduction: The Introduction should clearly state the purpose(s) of the article and summarize the rationale for the study of observation. Only pertinent references should be used.

Methods: The selection of observational or experimental subjects (patients or experimental animals, including controls) should be clearly described in the Methods section. The methods, apparatus, and procedures used should be described in enough detail to allow other workers to reproduce the results. References should be provided for established methods, including statistical methods. Methods that are not well known should be concisely described with appropriate references. Any new or substantially modified method(s) should be carefully described, reasons given for its use, and an evaluation made of its known or potential limitations. All drugs and chemicals used should be identified by generic name(s), dosage(s), and route(s) of administration. The numbers of observations and the statistical significance of findings should be included when appropriate. Patients' names, initials, or hospital numbers should not be used.

*Note that when reporting experiments utilizing human subjects, approval of the protocol by the sponsoring Institution's Committee on Human Subjects or its equivalent must be stated explicitly within the Methods section of the manuscript. In addition, the protocol for obtaining informed consent should be briefly described.

Results: Results should be presented in a logical sequence in the text, table(s), and illustration(s). Only critical data from the table(s) and/or illustrations(s) should be repeated in the text.

Discussion: Emphasis in the Discussion section should be placed on the new and important aspects of the study and the conclusions that can be drawn. Detailed data from the results section should not be repeated in the discussion. The discussion should include the implications and limitations of the findings and should relate the observations to other relevant studies. The link between the conclusion(s) and the goal(s) of the study should be carefully stated, avoiding unqualified statements and conclusions not completely supported by the data. The author(s) should avoid claiming priority and alluding to work that has not yet been completed. New hypotheses, when stated, should be clearly identified as such. Recommendations, when appropriate, may be included.

Potential Reviewers

To assist with a prompt, fair review process, authors are asked to provide the names, institutional affiliations, and e-mail addresses of 5 potential reviewers who have the

appropriate expertise to evaluate the manuscript. Failure to provide 5 potential reviewers may result in delays in the processing of your manuscript. Do not refer potential reviewers with whom you have a current or past personal or professional relationship. Do not recommend members of the *Journal's* editorial board. Authors may also provide the names of persons who should not be asked to review the manuscript. Ultimately, the Editors reserve the right to choose reviewers.

Article Types

The Journal of Adolescent Health publishes the following types of articles. Word count limits apply only to the main body of the manuscript, and do not include the title, references, or figure and table captions.

Original Articles are scientific reports on the results of original research. Text is limited to 3500 words with a 250-word structured abstract, 5 tables/figures, and 40 references. Original articles should include a 50-word **Implications and Contribution** summary statement.

Adolescent Health Briefs are scientific reports of original research that represent preliminary findings, small samples and newly described associations in unique populations. Briefs are limited to 1000 words, with a structured abstract of 150 words or less. A combined total of 2 figures and/or tables, and a maximum of 10 references will be accepted. Briefs should include a 50-word **Implications and Contribution** summary statement.

Review articles generally are solicited by the editors. If you would like to submit a review article the *Journal*, please submit a proposal letter, a detailed outline, and a preliminary reference list to the Managing Editor by e-mail at tor.berg@ucsf.edu. Systematic reviews and meta-analyses are preferred, though strong, evidence-based integrative and narrative proposals will be considered.

One or more of the Associate Editors will review the proposal and will advise the authors on proceeding to a full manuscript. This internal review will take place within four weeks of receipt of the proposal.

The final format of the article should include the introduction, review of the relevant literature, discussion, summary and implications section. Each review article must have a 200-word summary abstract. Review articles are limited to 4500 words, 5 tables/figures, and an unlimited number of references. Review articles should include a 50-word **Implications and Contribution** summary statement.

Clinical Observations: These case reports represent rare and new observations in the clinical arena. Papers in this format are limited to 1000 words and should include an introduction, concise discussion of the clinical observation, and discussion. Clinical observations should include a 200-word summary abstract. A combined total of 1 figure, table or illustration and 10 references will be accepted.

Editorial Correspondence: Letters regarding articles published in the *Journal* within the proceeding 6 months are strongly preferred. Letters should not exceed 400 words. This correspondence is published at the discretion of the Editor-in-chief and the Associate Editors. The authors of the article that is subject of the correspondence will be invited to respond.

Invited Commentaries: Commentaries are invited only, and will be solicited solely by the

editors. Commentaries serve as a forum for changes in adolescent healthcare training, economic issues, governmental health policies, international health, medical/scientific ethics, and meeting reports.

Journal Style

All aspects of the manuscript (tables, illustrations, and references) should be prepared according to the International Committee of Medical Journal Editors (ICMJE) requirements.

Grammar, Punctuation, and Usage. Grammar, punctuation, and scientific writing style should follow the *AMA Manual of Style*, 10th edition.

Abbreviations. Authors should provide a list of abbreviations on the title page. All acronyms in the text should be expanded at first mention, followed by the abbreviation in parentheses. The acronym may appear in the text thereafter. Do not use abbreviations in the title.

Acronyms may be used in the abstract if they occur 3 or more times therein. Generally, abbreviations should be limited to those defined in the *AMA Manual of Style*, 10th edition.

Uncommon abbreviations should be listed at the beginning of the article.

Units of Measure. Authors should use *Système International* (SI) values.

Proprietary Products. Authors should use nonproprietary names of drugs or devices unless mention of a manufacturer is pertinent to the discussion. If a proprietary product is cited, the name and location of the manufacturer must also be included.

References. Authors are responsible for the accuracy of references. References should be numbered consecutively in the order in which they are first mentioned in the text. Identify references in text, tables, and legends by Arabic numerals in parentheses. References cited only in tables or figure legends should be numbered in accordance with the sequence established by the first identification in the text of the particular table or figure. The titles of journals should be abbreviated according to the style used in the list of *Journals Indexed for MEDLINE*, posted by the NLM on the Library's web site.

Reference style should follow that of the , 10th edition, as shown in the following examples. The titles of journals should be abbreviated according to the style used in the list of Journals *AMA Manual of Style* Indexed for MEDLINE, posted by the NLM on the Library's web site.

<http://www.nlm.nih.gov/tsd/serials/lji.html>

Journal

1. Standard journal article:

References should list all authors when three or fewer; when four or more, only the first three should be listed, followed by et al.

Aalsma MA, Tong Y, Wiehe SE, et al. The Impact of Delinquency on Young Adult Sexual Risk Behaviors and Sexually Transmitted Infections. *J Adolesc Health* 2010;46:17-24.

DOI:10.1016/j.jadohealth.2009.05.018.

2. Corporate Author:

Center for Health Promotion and Education: Guidelines for effective school health education to prevent the spread of AIDS. *J Sch Health* 1988;58:142-8.

Books and Monographs

1. Personal Author(s):

Romer D, ed. *Reducing Adolescent Risk: Toward an Integrated Approach*. Thousand Oaks, California, Sage Publications, 2003.

2. Editor(s) Compiler(s), Chairman as Author(s):

Rosen DS, Rich M, eds. The Adolescent Male. Adolescent Medicine: State of the Art Reviews. Vol 14. Philadelphia, Hanley & Belfus, 2003:3.

3. Chapter in a Book:

Marcell AV, Irwin CE Jr. Adolescent Substance Use and Abuse. In: Finberg L, Kleinman RE, eds. Saunders Manual of Pediatric Practice, 2nd edition. Philadelphia: WB Saunders, 2002:127-139.

4. Agency Publication:

America's Children: Key National Indicators of Well-Being 2009. Washington, DC: Federal Interagency Forum on Child and Family Statistics, 2009.

Web site

World Health Organization. Good information practice essential criteria for vaccine safety web sites. Available at: http://www.who.int/vaccine_safety/good_vs_sites/en. Accessed January 13, 2010.

An effort should be made to avoid using abstracts as references. Unpublished observations and personal communications are not acceptable as references, although references to written, not verbal, communications may be inserted into the text in parentheses. References to manuscripts accepted but not yet published should designate the journal followed by (in press). All references must be verified by the authors against the original documents.

Tables

Any tables should be submitted as separate and individual files. Tables should be numbered consecutively, in order of citation in the text. Each table should be given a brief title; explanatory matter should be placed in a table footnote. Any nonstandard abbreviation should be explained in a table footnote. Tables should not rely on vertical lines for clarity or coherence and should contain as few horizontal lines as possible. Statistical measures should be identified as measures of variation such as S.D. or S.E.M. If data from another published or unpublished source are used, permission must be obtained and the source fully acknowledged. EES will accept files from a wide variety of table-creation software.

Figures

Any figures should be submitted as separate and individual files. Letters, and symbols should be clear and even throughout and of sufficient size that when figures are reduced for publication (to approximately 3 inches wide), each item will still be legible. Figures should be numbered consecutively, in order of citation in text. Each figure must have a legend typed in a separate document that you will upload to EES immediately after the illustration that it references. When symbols, arrows, numbers, or letters are used to identify parts of the illustrations, each should be identified and clearly explained in the legend.

The cost of color illustrations must be borne by the author(s).

If photomicrographs are to be submitted, the requirements for their presentation should be obtained from the Editor-in-Chief prior to submission.

If photographs of persons are used, either the subjects must not be identifiable or their pictures must be accompanied by written permission to publish the photograph.

If an illustration has been published, the original source must be acknowledged and accompanied by written permission from the copyright holder to reproduce the material. Permission is required regardless of authorship or publisher except for documents in the public domain. Guidelines for submitting your illustrations in an electronic format can be found by clicking on Artwork Guidelines at <http://www.ees.elsevier.com/JAH/>.

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- o Review author guidelines, article requirements, and instructions for submitting manuscripts through the Elsevier editorial system, located at <http://ees.elsevier.com/jah/>.
- o Cover letter
 - Disclosure of any prior publications or submissions with any overlapping information
 - A statement that the work is not under consideration elsewhere
 - Disclosure of any potential conflict of interest, real and perceived, for all named authors
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 - Name, address, e-mail address, telephone and fax number of the corresponding author
 - Sources of funding and acknowledgements of support and assistance
 - Disclosure of potential conflicts, real and perceived, for all named authors
 - Clinical trials registry site and number
 - List of abbreviations
- o Abstract, structured for original articles and briefs, summary for review articles and clinical observations
- o List of keywords
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 - References should be on a new page
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- o Figures, each saved as a separate file
- o Copies of prior and/or in press publications related to the current submission can be uploaded as separate files or e-mail to the Managing Editor at tor.berg@ucsf.edu

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